THE UNIVERSITY *of* EDINBURGH

THE UNIVERSITY *of* EDINBURGH

The role of illness-related shame and compassion in long-term health conditions

Anna Maddison

Doctorate in Clinical Psychology

The University of Edinburgh

May 2020

Acknowledgements

I would like to firstly thank the people who took part in this project. Their willingness to share both their time and experience to facilitate our understanding and knowledge is greatly appreciated.

Thank you to my supervisory team, Dr David Gillanders and Dr Ellie Caldwell, whose knowledge and expertise in the field kept me on track and filled me with confidence. A huge thank you to the Clinical Health Psychology team, in particular to Greg Halliday, Dr Audrey Mathews, Dr Jenny Strachan and Dr Lisa Harrow who made the groups possible, provided hours of useful and reflective discussion and, supported the project (and me) in every way they could. Thank you to Charlotte Smith whose patience and proficiency made the process as smooth as possible.

I am thankful for the kindness and patience of all my friends and family over the last three years. In particular, to Claire and David, for your unwavering support and encouragement to keep feeling my way forward. Finally, and vitally, thank you to Colin. Who has been my stability, strength, and partner in blissful days of escapism and adventure.

Table of Contents

The role of illness-related shame and compassion in long-term health conditions 1

Acknowledgements 2

Portfolio Thesis Abstract 4

Illness-related shame and associated outcomes: A systematic review 8

Abstract 9

Introduction 11

Methods 15

Results 17

Discussion 35

Conclusion 39

References 41

Group Compassion Focused Therapy for diverse physical health conditions: A multiple baseline case series 49

Abstract 50

Introduction 52

Method 57

Results 62

Discussion 76

References 81

Thesis portfolio references 87

Appendices 102

Appendix One: References of studies with a global measure of shame 104

Appendix Two – Weekly battery scores 107

Appendix Three – Study Protocol 114

Appendix Four – Participant Information Sheet and Consent Form 148

Appendix Five – Ethical approval 152

Appendix Six – Journal of Behavioral Medicine submission guidelines 156

Portfolio Thesis Abstract

Objective

Compassion Focussed Therapy (CFT) was initially developed to treat people with high levels of shame proneness and self-criticism. In CFT, shame is conceptualised as transdiagnostic in psychological distress. The prevalence of psychological distress (including shame) in people living with long-term physical health conditions (LTCs) is well evidenced. There is interest in the use of compassion-focussed interventions for people with LTC's and initial evidence that they can reduce distress and increase self-management behaviours. The presented systematic review explores the current evidence for illness-related shame (IRS) across physical health populations and identifies associated psychosocial factors. The empirical paper investigates the process of change for individuals with various LTCs during a CFT group intervention.

Methods

Three key databases were searched to identify studies with a measure of illness-related shame (IRS). Papers that met the inclusion criteria were quality assessed and results synthesised to provide narrative summary. A multiple baseline, single case experimental design was used to track changes in compassion, illness cognitions, self-efficacy, social functioning and psychological wellbeing, with daily and weekly measures, over a ten-session structured CFT intervention.

Results

Results of the review indicated illness-related shame has been tested in a small but diverse number of health conditions and is prevalent in all conditions studied. Associated factors were heterogenous however, the presence of IRS was most commonly associated with reduced wellbeing, increased

anxiety and depression, and cognitive fusion. In the CFT group, improved self-compassion was reported across all individuals. Changes on measures related to psychological adjustment were not consistent across individuals. The process of change was gradual, with quantifiable change most commonly demonstrated within the last four sessions of the group.

Conclusions

IRS is present across a range of LTC groups. Further research is needed to identify differences in the prevalence between LTC populations and clarify the role of IRS as a target for psychological intervention. A CFT group for various and multiple health conditions was effective in producing changes in self-compassion. A clearer understanding of the link between compassion and adjustment to illness is sought to inform changes to intervention or measurement, in order to produce and demonstrate therapeutic change.

Lay summary

The number of people living with long-term health conditions (LTCs) such as heart disease, diabetes and cancer is growing. These conditions usually mean people have to change medication, diet and other lifestyle factors. Living with these conditions can make everyday tasks more difficult and people often need more help from others. They might not be able to work or socialise like they did before their illness. These changes, on top of the symptoms of the illness itself, means that mental health difficulties such as anxiety and depression are more common in people who have long-term health conditions.

Research shows that shame or self-criticism can affect how difficult someone finds it to adjust to living with a health condition. People who are less able to be kind to themselves can find it more difficult to adjust to a 'new normal' created by their illness. Shame about illness is thought to affect how people feel about themselves and how they use the healthcare system. Compassion-Focused Therapy (CFT) targets both shame and self-compassion. Therefore, research is beginning to look at how CFT can be used with people who have chronic illnesses.

This thesis project first describes the evidence that shame about living with LTCs exists for people with different illnesses. It describes the research which has measured illness-related shame, and highlights factors which are related to illness-related shame. Three large databases were searched. It found that illness-related shame had been studied in a small but varied group of health conditions. No studies had described whether the level of shame reported in their study was high or low. This meant it was not possible to say whether there are differences in how much illness-related shame different illness groups experience. The review also showed that illness-related shame is linked to anxiety, depression and thinking styles. Many different factors were linked to shame but research is needed to make these relationships clearer. These were psychological, social and physiological factors. More research is needed to understand how illness-related shame is involved

in good psychological wellbeing, and if it would be a good target in psychological interventions for LTCs.

The second paper describes a group intervention using CFT with people who have varied health conditions. This is a new intervention because groups are usually separated by health condition. The group lasted 10 weeks and aimed to help participants to have more compassion in their lives, and to help their adjustment to living with illness. Six participants were asked to answer three questions each day and a set of questionnaires each week. Changes in scores could be tracked over the group sessions. This meant it was possible to see which factors changed, and to see when they changed. The results showed the CFT group was helpful and all participants reported improved self-compassion. Some participants described having less compassion for other people. Changes in adjustment to illness were not the same for all participants. This showed that group CFT for people with varied health conditions is effective at improving self-compassion. It suggests that the group might need to include other strategies to improve adjustment. Suggestions about the research that is needed to understand this better are described.

Illness-related shame and associated outcomes: A systematic review

Anna Maddison[12], Greg Halliday [2] and Dr David Gillanders [1]

[1]Clinical & Health Psychology, School of Health and Social Science, University of Edinburgh

[2] Clinical Health Psychology, NHS Lothian

Author Note:

No known conflicts of interest to disclose.

Corresponding author: Anna Maddison, S0819674@ed.ac.uk, Clinical & Health Psychology, University of Edinburgh, School of Health in Social Science, Teviot Place, Edinburgh, EH8 9AG.

Written for submission to the *Journal of Behavioral Medicine*. See Appendix Six for journal submission guidelines.

Abstract

Objectives

Shame has been highlighted as a transdiagnostic variable involved in multiple psychopathologies. This review aimed to explore the prevalence and impact of shame specifically related to living with long term health conditions (LTCs). This would indicate whether targeting illness-related shame (IRS) in psychological interventions is appropriate across LTC populations and have implications for the provision of health care.

Methods

Databases (Ovid; PsychInfo and Embase) were searched on 2nd February 2020. Search terms from three categories (shame; chronic illness; specifically named illnesses) were combined. Inclusion criteria included: validated scale of IRS; LTC population; no primary learning disability, substance misuse or mental health disorder.

Results

1638 results were screened for inclusion with 126 full texts accessed. Twenty-one studies met inclusion criteria. Illness related shame (IRS) has been studied in six health groups (HIV, Breast Cancer, Asthma, Inflammatory Bowel Disease (IBD), Psoriasis, Burns). It was not possible to compare levels of shame between different illness populations, due to heterogeneity in measures. Twenty-two factors associated with shame were identified, with anxiety, depression and psychological wellbeing the most commonly studied.

Conclusions

The study of illness related shame has been applied to a limited number of groups and with significant heterogeneity of measures used and associated factors reported. The literature confirms the presence of IRS, which has implications for the content of psychological intervention and delivery of healthcare services. This indicates use of compassion-focussed interventions is

appropriate; however, further research is needed to clarify if the need to target IRS is similar across population groups.

Keywords

Chronic Illness; Illness Related Shame (IRS); Systematic Review; Shame

Illness-related shame and associated outcomes: A systematic review

Introduction

Shame is defined as a secondary, self-conscious emotion. It is provoked by negative self-evaluation involving a sense of inferiority, inadequacy, or difference (Kaufman, 1996; McFall & Johnson, 2009). From an evolutionary perspective, shame arises to protect social connection and inclusion. By facilitating the identification of personal characteristics (e.g. appearance, personality traits, behaviours) that are deemed unacceptable within the social group, shame allows us to modify these aspects to maintain our position in a group and survive (Gilbert, 1997; Kaufman, 1996). The evolutionary importance of attachment and sense of belonging ensures that the emotive response when these are threatened is sufficiently aversive to feel compelled to fix the problem (Baumeister & Leary, 1995). Shame can be experienced as an acute painful episode during a moment in which one's shameful attribute is exposed (domain specific shame), or as a chronic affective state in which shame is internalised and persistent (global shame), creating a background of self-consciousness and social discomfort impacting upon multiple aspects of life (Dolezal & Lyons, 2017). Both global and domain specific shame have been theorised to be inversely related to state emotion, when mood deteriorates, shame increases (Gilbert & Andrews, 1998; Kim et al., 2011). Domain specific shame is thought to generalise to the whole self at these times, rather than regarding a specific trait (Gilbert & Andrews, 1998).

In the context of psychological wellbeing, shame is considered both a transdiagnostic aetiological contributing factor, and a secondary consequence, of many mental health difficulties (Clark, 2012). Those experiencing high levels of global or domain specific shame find it difficult to generate a sense of safety, warmth or contentment in their relationships with others and themselves. They are also highly sensitive to potential social threat (Gilbert, 2000). Shame has been linked to the experience of depression, social anxiety, phobia, eating disorders, trauma, personality disorders and psychosis (Gilbert & Miles, 2014; Harder et al., 1992).

Whilst self-conscious emotions are often discussed interchangeably, the experience of shame is different to that of other self-conscious emotions such as guilt and embarrassment (Tangney et al., 1996). Guilt refers to the sense of having done something wrong, either real or imagined, which breaks a social norm (Baumeister et al., 1994). Embarrassment similarly refers to an often discrete, time limited behaviour or act e.g. a mistake made in public. Shame on the other hand, refers to the whole self and core identity as being below standard or defective. All self-conscious emotions require an understanding of other's expectations and social rules, in order to understand one's actions to be contradictory to these or hurtful to others (Gilbert, 2014). The experience of these emotions has been shown to activate different brain regions, involve different cognitive patterns and impact us differently (Takahashi et al., 2004; Tangney et al., 1996). For example, the experience of shame is more strongly associated with symptoms of depression than guilt, across age, gender and ethnicity (Kim et al., 2011).

The body can be a significant trigger and source of shame. This can be related to early experiences of trauma and abuse, as well as to living with an illness perceived as unacceptable to the values of society or the individual (Clark, 2012). Individuals can see their conditions as defects, inadequacies or personal shortcomings (Lazare, 1987). Illness-related shame can be provoked by multiple aspects of illness including: visible and hidden symptoms, additional needs, public perception of the illness or, degree of involvement in its contraction (Gilbert & Miles, 2014; Werner et al., 2004). From a social perspective, illness is threatening to our desirability within a group and ability to function within previous roles. Given the utility of shame in protecting social relations, these factors can be highly distressing and are perceived as a threat. As chronic illness cannot be cured, this sense of being different or inferior to others can be ongoing and pervasive.

Living with chronic illness is consistently linked with poorer physical, social and psychological functioning. Research indicates people living with long term health conditions are two to three times more likely to experience a mental health problem than the general population (Naylor et al., 2012). Overall psychological wellbeing is consistently reported to be lower in LTC populations (Health

Organization Regional Office for Europe, 2017). This encompasses poorer quality of life and quality of relationships, a decreased sense of independence and increased feelings of isolation (Casati et al., 2000; Harandi et al., 2017). Shame can contribute to each of these. In some health conditions (e.g. HIV) shame has been implicated in non-disclosure of status; this in turn reduces the opportunity for medical, social and peer support to live well with a health condition (Hutchinson & Dhairyawan, 2017). Such non-disclosure, or fear of the shameful attribute being exposed, reduces the opportunity for social connectedness and achievement, leading to low mood, reduced quality of life and isolation. Research is now exploring the mediators of the relationship between illness-related shame and psychological distress. A recent study demonstrated that the relationship between illness related shame, psychological distress and quality of social relationships was in part explained by fears of compassion and experiential avoidance (Trindade et al., 2018).

Self-criticism is a key component of shame (Gilbert & Procter, 2006). It facilitates the negative self-evaluation which is implicated in various mental health difficulties, with links to depression mediated by perfectionism and reduced self-compassion (James et al., 2015; Mehr & Adams, 2016). In LTC populations self-criticism has been linked to poor psychosocial adjustment (Dunkley et al., 2012) and increased physical symptom severity (Hyphantis et al., 2013). Those experiencing high shame and self-criticism are less likely to seek or accept help, and the associated mental health difficulties such as depression reduce motivation and energy to engage in activities of illness self-management (Gilbert et al., 2006; Kim et al., 2011; Trindade et al., 2019).

Within a healthcare context, it is theorised that the avoidance of an acute episode of shame can lead to failure to seek treatment or disclose all relevant information (Dolezal & Lyons, 2017). In order to provide effective care, practitioners are likely to enquire about pre-existing health conditions, symptoms and health behaviours such as diet, exercise and smoking. Such topics have the ability to trigger shame-avoidance behaviours if the individual perceives themselves to be below the expected standard. Avoiding such situations, or not disclosing information, can lead to insufficient or inappropriate care, which in turn may lead to further ill health (Lazare, 1987). Where

shame becomes chronic there is evidence for the release of cortisol and pro-inflammatory cytokines in the body. These in turn have been linked to heart disease, weight gain and reduced immune function (Dolezal & Lyons, 2017), again having the potential to diminish physical health further. Finally, the experience of shame has also been associated with alcoholism, addiction and eating disorders, which are manifested as coping strategies (Dolezal & Lyons, 2017; Wiechelt, 2017). The evidence for the biopsychosocial impact of shame indicates it may be a beneficial target for psychological intervention, with the potential for transdiagnostic improvement in psychological and physical wellbeing.

Measuring the experience of shame is inherently difficult due to the subjective nature of the internal experience. This is compounded by the nature of shame itself, in which individuals seek to conceal or underplay their experience in order to avoid exposure of their perceived flaws. Tools have been generated to measure global and domain specific experiences of shame. Those measuring global shame can be prone to be influenced by mood-state effects (Andrews et al., 2002) and allow for the inclusion of multiple domains of shame within an individual. With regards to illness-related shame, there is heterogeneity across measures. Some measures can be applied across health populations and others are designed for specific illness groups. Many of these tools lack conceptual clarity around shame, often stating the measurement of shame, and including questions specifically regarding guilt or stigma. This speaks to the difficulty of disentangling self-appraisals, self-conscious emotions and their consequential behaviours in order to gain a pure measure of one emotion. Whilst this is reflective of the human experience, it would be beneficial to have a more rigorous definition to allow evidence-based development of theory and intervention.

Despite a growing understanding of how shame can impact upon an individual and the role of illness-related shame in psychological and physical outcomes, it is not clear whether the experience of illness-related shame is universal or common across chronic illness populations. This review aims to assimilate evidence for the experience of illness-related shame across individuals living with any long-term health condition. It will explore, where reported, associated psychological,

functional or social outcomes, with the aim of contributing to the evidence base suggesting illness-related shame is a potential target for psychological intervention in all chronic illness populations.

Review Questions:

- How prevalent is illness related shame across long term condition populations?
- What psychosocial factors are associated with illness related shame?
- Is there risk of bias in the available published literature relating to illness-related shame?

Methods

Protocol and registration:

A review protocol was registered with Prospero on 12th November 2019, registration number CRD42019151035.

Eligibility criteria:

Research published or in press by 2nd February 2020 was included. Only studies published in English language were included. Any quantitative methodology was eligible, including but not limited to observational, interventional and randomised control trials. Comparison groups were not essential however, if two illness groups were compared, both sets of data were extracted. Where interventional studies reported pre- and post-intervention measures, only pre-intervention scores were extracted.

Any long-term health condition population was deemed eligible. A condition was accepted for inclusion if it required ongoing management and was not expected to be cured, as described by Scottish Government (Scottish Government, 2015a). This included conditions currently labelled 'functional' or 'somatic' which cause persistent physical symptoms and require ongoing management.

Exclusion criteria included: 1) populations with a primary mental health, learning disability or substance misuse diagnosis; 2) studies measuring illness-related shame in parents/family/carers; 3) <18 years old; 4) one item measures or generic measures of shame i.e. not illness-related.

Information Sources:

Databases searched included: Ovid, PsychInfo, and Embase. References of articles selected for inclusion were then hand searched and relevant articles screened for inclusion.

Search:

Search terms are displayed in table one. Search terms were combined to include shame with any of the chronicity terms, illness types or specific terms. Specific illness terms chosen for inclusion were guided by examples given in the 'NHS data dictionary' definition of LTCs (NHS Digital, 2020)

Table One: Search terms by category

Shame	**Chronicity**	**Illness type**	**Specific**
Shame	*long term*	*disorder**	*COPD*
	persistent	*condition**	*Asthma*
	chronic	*illness**	*Epilepsy*
	somatic	*symptom**	*HIV*
	functional	*syndrome**	*Cancer*
	medically unexplained	*disease**	*Diabetes*
		pain	*IBS*
			Heart disease

Study Selection:

Titles and abstracts of all results were screened. Full text versions of those eligible were sourced and reviewed to confirm eligibility for final inclusion in the systematic review. This was undertaken by one individual. A sample equating to 20% of included articles were checked for

consistency by GH, an Assistant Psychologist in the Clinical Health Psychology department with Masters level training in research methodology.

Data collection process

A checklist of data and key information to be extracted from each study was developed and used to ensure all information was sought and noted if not available. The required data included: illness population, country of study, study methodology, age range, gender, measure used, results of shame measurement, any additional related factors reported e.g. psychological or functional outcomes.

Risk of bias

The Quality Assessment Tool for Systematic Reviews of Observational Studies (QATSO; (Wong et al., 2008) was used to assess risk of bias. This contains five items relating to external validity, reporting clarity, bias, and confounding factors. The QATSO has been used in previous systematic reviews of observational studies (Davids & Roman, 2014; Roman & Frantz, 2013). After an initial screening of full articles the tool was altered to include an additional question, this related to reporting bias as it was noted a proportion of papers did not report the results of all measures used. A percentage score is reported to broadly reflect a range of weak (0-33.9%), moderate (34-66.9%) or strong (67-100%) quality. These figures were used to aid a descriptive of quality across identified articles.

Results

Search results

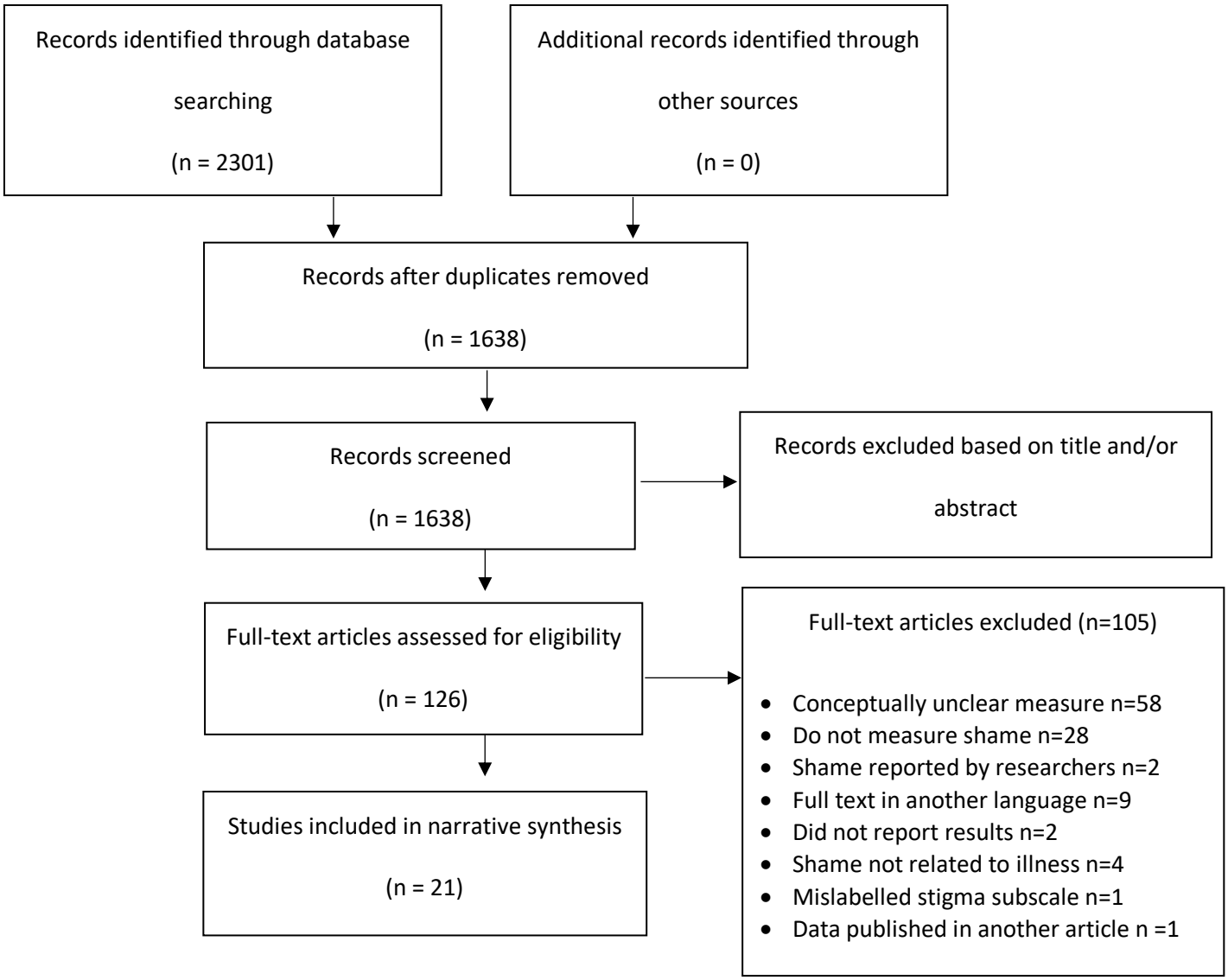
The initial search found 1638 articles after deduplication. Following screening of titles and abstracts, 126 studies were accessed for full review. Of these, 105 were excluded based upon the

measurement of shame or the published article being published in another language. Twenty-one studies were included for narrative review as shown in figure one.

Study characteristics

Twenty-one studies met inclusion criteria (characteristics in Table Two). Fourteen (66.66%) were cross-sectional surveys, five prospective cohort (23.8%), one case series (4.76%) and one case control (4.76%). Seven papers (33.33%) were from the same research group.

Figure 1: PRISMA Diagram



Population characteristics

Six health conditions were analysed specifically (breast cancer N=8, HIV N=5, IBD N=3, Asthma N=1, Psoriasis N=1, Burns N=1) and two studies reported measures from samples with multiple and various health conditions. Table Three describes participant characteristics. A total of 3990 participants were included across all studies (mean N = 181.66, median = 166, range 1-429). Ten studies included only females (45.45%).

Table Two: Study characteristics

Study	Year	Country	Health Population	N	Study Design
Boquiren et al.	2013	Canada	Breast Cancer	150	Cross sectional
Castonguay et al.	2017	Canada	Breast Cancer	149	Prospective
Fellows et al.	2015	UK	Asthma	1	Case Series
Hill et al.	2011	UK	Breast Cancer	355	Prospective
Lahousen et al.	2016	Germany	Psoriasis	171	Cross sectional
Minja et al.	2019	Tanzania	HIV	200	Prospective
Moreira & Canavarro	2010	Portugal	Breast Cancer	56	Prospective
Moreira et al.	2010	Portugal	Breast Cancer	173	Cross sectional
Neufeld et al.	2012	USA	HIV	271	Cross sectional
Persons et al.	2010	USA	HIV	247	Cross Sectional
Pila et al.	2018	Canada	Breast Cancer	173	Prospective
Sikkema et al.	2009	USA	HIV	256	Cross sectional
Taal & Faber	1998	Netherlands	Burns	429	Cross sectional

Trindade et al.(a)	2018	Portugal	Various	115	Cross sectional
Trindade et al.(b)	2018	Portugal	IBD	120	Cross sectional
Trindade et al.	2017	Portugal	Various	254	Case control
Trindade et al.	2019	Portugal	IBD	53	Cross sectional
Trindade et al.(c)	2018	Portugal	Breast Cancer	75	Cross sectional
Trindade et al.	2020	Portugal	IBD	161	Cross sectional
Trindade et al.(d)	2018	Portugal	Breast Cancer	82	Cross sectional
Vincent et al.	2017	USA	HIV	299	Cross sectional

Table Three: Participant characteristics

Study	Year	Mean Age (SD)	Age Range	Gender	Other
Boquiren et al.	2013	49.47 (8.81)	26-75	100% female	Attending psychotherapy group for body consciousness
Castonguay et al.	2017	55.34 (10.5)	30-79	100% female	
Fellows et al.	2015	37	-	100% female	

Hill et al.	2011	-	-	100% female	
Lahousen et al.	2016	50.6 (13.3)	-	43.90% female	
Minja et al.	2019	Median 30	-	100% female	
Moreira & Canavarro	2010	52.39 (7.77)	37-68	100% female	
Moreira et al.	2010	53.44 (8.8)	32–81	100% female	
Neufeld et al.	2012	-	-	49.07% female	History of childhood sexual abuse
Persons et al.	2010	Female: 43.3 (7.1) Male: 41.1 (6.7)	-	52.2% female	
Pila et al.	2018	55	28- 79	100% female	
Sikkema et al.	2009	-	-	51.5% female	History of childhood sexual abuse
Taal & Faber	1998	38.3	16-90	36% female	Burns requiring hospital admission
Trindade et al.(a)	2018	24.27 (4.54)	-	83.48% female	
Trindade et al.(b)	2018	37.90 (11.29)	19-77	69.17% female	

Trindade et al.	2017	IBD: 36.73 (10.73). Mixed: 37.74 (11.29)	IBD: 19 – 76 Mixed: 18 – 76	IBD: 67.7% female Mixed: not reported	
Trindade et al.	2019	40.20 (11.65)	18-65	66% female	
Trindade et al.(c)	2018	57.60 (10.18)	36-85	100% female	
Trindade et al.	2020	36.73 (10.73)	19-76	67.7% female	
Trindade et al.(d)	2018	50.21 (9.76)	28-76	100% female	
Vincent et al.	2017	55.23 (4.84)	-	31.77% female	Older adults. Required BDI score >10

Measurement of illness related shame

Over the 22 studies, nine validated measures of illness-related shame were used (Table Four). Four of these related to body-shame (Objectified Body Consciousness Scale: Shame subscale; Weight and Body Related Shame and Guilt (WEB-SG) scale: Shame subscale; Experience of Shame Scale (ESS): Bodily shame subscale; Touch-Shame-Disgust questionnaire (TSD-Q) – Shame subscale; (Andrews et al., 2002; Conradt et al., 2007a; Kupfer et al., 2005; Mckinley & Hyde, 1996). Two pertained to HIV specifically, the HIV and Abuse Shame Related Inventory (HARSI) and a 13-item unnamed measure (Persons et al.,2010). One referred to shame related to a burn injury (Taal & Faberb, 1998). Two measures referred to the entire illness experience and could be used across health conditions ((PBIQ shame subscale; Birchwood et al., 2012), CISS (Trindade et al., 2017)). The PBIQ was developed as a measure of shame relating to mental health conditions, however, was used by the authors to measure illness-related shame.

Levels of illness related shame reported

Results of each study are displayed in Table Five. Outcome scores of illness-related shame were reported in 18 studies. Three studies reported using a measure of illness-related shame but did not report the results of this within the article (Hill et al.,2011; Moreira et al., 2010; Trindade et al., 2018). Four studies reported scores in a format that did not allow comparison to other studies using the same measure. Castonguay (2017) and Pila et al. (2018) both used the WEB-SG and reported an overall mean response. Minja et al. (2019) reported a median score of the HARSI which is not directly comparable to norms reported as means. Taal & Faber (1998) utilised a version of the burn measure which could not be sourced in the literature and was deemed not to represent the original measure in systematic review of the tool (Yoder et al., 2010). Moreira & Canavarro (2017) also reported an item-level mean. Trindade, Ferreira & Pinto-Gouveia (2017) reported itemised questions means for the CISS. No papers discussed whether the scores of illness-related shame could be categorised as high or low, or compared to other illness groups. One paper reported scores for two

illness groups (IBD & a mixed sample, (Trindade et al., 2017) however, no statistical comparison was made of scores on the measure.

Factors associated with Illness-related shame

Twenty-two factors were significantly correlated to higher IRS (see Table Five): depression (N=3; Hill et al., 2011; Trindade et al., 2017; Trindade et al., 2018c), cognitive fusion (N=1; Trindade et al., 2018c), committed action (N=2; Trindade et al., 2020; Trindade et al., 2018d), anxiety (N=2; Hill et al., 2011; Trindade et al., 2017), severity of symptoms (N=1; Trindade et al., 2020), exercise (N=1; Castonguay et al., 2017), fears of compassion (N=1; Trindade et al., 2018a), experiential avoidance (N=2; Trindade et al., 2018a; Trindade et al., 2020), social relationships (N=2; Trindade et al., 2018a; Trindade et al., 2020), medication use (N=1; Minja et al., 2019), unprotected sex (N=1; Sikkema et al., 2009), body image (N=2; Moreira et al., 2010; Trindade et al., 2018c), health related quality of life (HRQoL, N=1; Persons et al., 2010), psychological health (N=2; Trindade et al., 2018a; Trindade et al., 2020), emotional wellbeing (N=1; Persons et al., 2010), global wellbeing (N=1; Persons et al., 2010), social wellbeing (N=1, Persons et al., 2010), cognitive functioning (N=1; Persons et al., 2010), post traumatic stress (PTSD, N=1; Taal & Faber, 1998), self-judgment (N=1; Trindade et al., 2017), self-compassion (N=1; Trindade et al., 2017), stress (N=1; Trindade et al., 2017), and age (N=1; Trindade et al., 2020).

Predictors or moderators of illness-related shame were: illness symptoms (N=2; Trindade et al., 2018a; Trindade et al., 2017) gender role socialisation (N=1; Boquiren et al., 2013), surveillance of body (N=1; Boquiren et al., 2013), mastectomy (N=1; Moreira & Canavarro, 2010), and body weight and pre-illness body weight fluctuations (N=1; Pila et al., 2018).

IRS was demonstrated to have a direct impact on: cognitive fusion (N=2: Trindade et al., 2018b; Trindade et al., 2018c), psychological quality of life (N=1; Trindade et al., 2018b), self-judgment (N=1; Trindade et al., 2017), and depression (N=2; Trindade et al., 2017; Trindade et al., 2018c). These studies do not describe causality, however, use path analysis to begin to explore where IRS may fit in relation to other significant factors associated with living with a LTC.

Large effect sizes or correlations were reported for body image, weight, cognitive fusion, quality of life, self-judgement and experiential avoidance. Small effect sizes or correlations were reported for self-compassion and age. Psychological health, social relationships and depression were reported with a range of effect sizes or correlations falling across the small to moderate ranges.

Table Four: Measures of illness-related shame

Measure	Author	Scale Description	Population validated	Mean (SD) in original paper
Burn Specific Health Scale – short version (BSHS-SV) – Shame subscale	Version of scale not found in literature	n/a	n/a	n/a
Chronic Illness Shame Scale (CISS)	Trindade et al., 2017	7 items Scored: 0-4 Range: 4-28	Mixed sample of long-term health conditions	Not reported
Experience of Shame Scale (ESS): Bodily shame subscale	Andrews et al., 2002	4 items Scored: 1-4 Range 4-16	Non-clinical student	9.82 (SD = 3.40)
HIV and Abuse Shame Related Inventory (HARSI): HIV Related Shame subscale	Neufeld et al., 2012	14 items Scored: 0-4 Range 0-50	HIV & childhood sexual abuse	17.1 (13.4)
HIV and Abuse Shame Related Inventory (HARSI): Impact of HIV-related shame on behaviour subscale	Neufeld et al., 2012	10 items Scored: 0-4 Range: 0–14	HIV & childhood sexual abuse	3.1 (4.6)
Objectified Body Consciousness Scale: Shame subscale	Mckinley & Hyde, 1996	8 items Scored: 1-7 Range: 1-7	Women	3.25 (1.04)

Personal Beliefs about Illness Questionnaire (PBIQ): Shame subscale	Birchwood et al., 2012	4 items Range not reported	First episode of psychosis – non depressed	7.7 (2.4)
Touch-Shame-Disgust questionnaire (TSD-Q) – Shame subscale	Kupfer et al., 2005	Full text not available in English		
Weight- and Body-Related Shame and Guilt (WEB-SG) scale: Shame subscale	Conradt et al., 2007b	6 items Scored: 0-4 Range: 0-24	Non-clinical obese	10.69 (6.66)

Table Five: Scores of IRS and associated factors

	Measure	Mean	Standard Deviation	Associations with shame
Boquiren et al., 2013	Objectified Body Consciousness Scale: Shame subscale	3.78	1.22	Gender role socialisation and surveillance accounted for 46% of variance in body shame
Castonguay et al., 2017	Weight- and Body-Related Shame and Guilt (WEB-SG) scale: Shame subscale	2.24	0.91	Higher shame related to less frequent moderate exercise undertaken
Fellows et al., 2015	Personal Beliefs about Illness Questionnaire (PBIQ): Shame subscale	16	-	N/A

Hill et al., 2011	Experience of Shame Scale (ESS): Bodily shame subscale	Not reported	Not reported	High shame associated with major depression and generalised anxiety disorder
Lahousen et al., 2016	Touch-Shame-Disgust questionnaire (TSD-Q) – Shame subscale	Median = 2	-	N/A
Minja et al., 2019	HIV and Abuse Shame Related Inventory (HARSI)	Median 16	IQR: 12, 25	Negatively related to attitudes towards long term use of ART
Moreira & Canavarro, 2010	Experience of Shame Scale (ESS): Bodily shame subscale	At surgery: 1.32 6 months: 1.75	At surgery: 0.56 6 months: 0.79	Having mastectomy predicted higher levels of body shame at 6 months
Moreira, et al., 2010	Experience of Shame Scale (ESS): Bodily shame subscale	Not reported	Not reported	Significant correlation with Body Image Scale (r = .68, p <.001)
Neufeld et al., 2012	HIV and Abuse Shame Related Inventory (HARSI)	17.1	13.4	N/A
Persons et al., 2010	Unnamed 13 item measure. ? HARSI	Female: 14.1 Male: 14.6	Female: 11.6 Male: 10.7	Predictive of poorer HRQoL (- 0.33, p < 0.001), emotional well-being (-0.37, p<.01), function and global well-being (- 0.33, p<.01), social well-being (-0.17, p<.05), cognitive functioning (-0.29, p<.01)
Pila et al., 2018	Weight- and Body-Related Shame and Guilt (WEB-SG) scale: Shame subscale	9-months: 2.22 12-months: 2.53	9-months: 0.89 12-months: 0.89	Higher weight cycling in adulthood related to higher levels of shame at posttreatment. Higher than average body weight related to increased levels of weight-related shame among women with stable weight throughout adulthood (= .61, p < .001)

		15-months: 2.19	15-months: 0.93	
Sikkema et al., 2009	HIV and Abuse Shame Related Inventory (HARSI)	Female: 17.2 Male: 18.5	Female: 13.7 Male: 13.2	Impact of shame on behaviour predictive of unprotected sex (univariate analysis: OR = 4.25, *p*<.01; multivariate analysis: OR = 3.34, *p*<.05)
Taal & Faber, 1998	Burn Specific Health Scale – short version (BSHS-SV) – Shame subscale – one item removed	>31%	Not reported	Correlated with posttraumatic stress as measured by the IES (*r*=0.61)
Trindade et al., 2018a	Chronic Illness Shame Scale (CISS)	6.58	6.82	Positive correlation to: Fears of compassion (*r* .54, p <.00*1*), Experiential avoidance (*r* = .42, *p* <.001). Negative correlation to: Social relationships (*r* = -.39, *p* <.001), Psychological health (*r*=.39, *p* <.001)
Trindade et al., 2018b	Chronic Illness Shame Scale (CISS)	8.37	6.26.	Symptoms predicted shame (effect size = 0.39 *p* <.001). CISS directly predicted CFQ-CI (effect size = 0.72, *p* < .001). Significant effect on psychological QoL (total effect size = − 0.61, *p* < .001); direct effect size = − 0.32, *p* < .01); indirect effect size =− 0.29, *p <0.01).* Effect on QoL significantly mediated by the mechanisms of CFQ-CI (95% CI − 0.46 <> − 0.15, *p* < .001)
Trindade et al., 2017	Chronic Illness Shame Scale (CISS)	Itemised scores only	Not reported	Correlated to: self-compassion *r* = -.33, p<.001), self-judgment (*r = .61, p*<.001), depression (*r* = .58*, p*<.001), anxiety (*r* = .37, *p*<.001), stress (*r* = .54, *p* <.001). IBD symptoms direct moderate effect on IRS (effect size = .41, *p*< .001. CISS direct large effect on self-judgement (effect size =.61; *p*<.001) and small effect on depressed mood (effect size =.17, *p* <.05). Self-judgment mediated relationship between

				IRS and depressed mood (effect size = .34, *p*< .001). CISS total effect size = .51 (p < .001) on depressive symptomatology.
Trindade et al., 2019	Chronic Illness Shame Scale (CISS)	5.09	5.07	N/A
Trindade et al., 2018c	Chronic Illness Shame Scale (CISS)	6.75	6.13	IRS significantly affected by body dissatisfaction (effect size = 0.53, *p<.001).* Correlated to: Body image dissatisfaction (CISS; *r*= 0.53; *p*< 0.001); Chronic illness-related cognitive fusion *(r* =−0.64; *p*< 0.001); Depression symptoms (*r*= 0.68; *p*< 0.001). IRS direct prediction of cognitive fusion (effect size = 0.64, *p*<.001) and depression (effect size = 0.37, *p*<.001). IRS mediated relationship between body image dissatisfaction and cognitive fusion. Total effect size on depression =.79.
Trindade et al., 2020	Chronic Illness Shame Scale (CISS)	8.64	6.27	Chronic illness–related shame positively associated with experiential avoidance effects (effect size = .65, *p<.001),* uncommitted action (effect size = .39, *p<.001)* and IBD symptomology (effect size = .41, *p<.001).* It was negatively associated with age (effect size = -.24, *p<.01),* psychological health (effect size = -.22, *p<.001)* and social relationships (effect size = -.21, *p<.01)*
Trindade et al., 2018d	Chronic Illness Shame Scale (CISS)	Not reported	Not reported	Correlation with committed action (CAQ-8) *r* = -.36, *p*<0.01
Vincent et al., 2017	HIV and Abuse Shame Related Inventory (HARSI)	Total: 17.84 MSM: 18.57 Heterosexual men: 19.98 Heterosexual women: 15.41	Total : 13.1 MSM: 13.17 Heterosexual men: 13.03 Heterosexual women: 12.89	HIV shame accounted for 36.0% of the variance in depression and 29.3% of the variance in loneliness

Risk of bias and quality

Inter-rater reliability on the QATSO was high, with percentage agreement ranging from 75% to 100% (mode = 83.33%). One study fell within the range for weak quality, eleven within the moderate range and ten within the high-quality range, as shown in Table Six. Across studies, validity of the illness experience was met through recruitment methods however, around a third of sampling methods required participants to be part of a support association and so may have limited a fully representative sample of the population. Response and drop-out rates were poorly reported across studies (present in 45% of studies) further limiting the scope to generalise findings without assurances those struggling most with their illness (or illness related shame) were not lost to attrition / self-excluded. Internal validity was moderate to high, with many confounding variables explored or controlled for and reported in modelling studies. There was significant heterogeneity in reporting results of measures used across studies, with a significant proportion reporting only correlation or regression analysis without any descriptive statistics or comment of the distribution of scores across populations.

One case series (Fellows, 2015) was reviewed as high quality, however, is limited in external validity due to the nature of the methodology. Although overall quality in the individual studies from the research group in Portugal are moderate, when taken as a reflection of the field at present some caution must be taken in extrapolating results. It is not clear if the populations from each of these seven studies is discrete or if individuals may have taken part in more than one study. The samples having been recruited from the same hospitals and support associations likely leads to a homogenous group and whilst education levels are reported in each study, socioeconomic factors are not.

Table Six: Scoring on QATSO bias assessment

Study		QATSO Items						
Study	Year	Sampling method	Objective measurement of illness	Reported response rate	Reported control for confounding factors	All measures reported	Primary or secondary data	Total
Boquiren et al.	2013	x	+	x	-	+	+	Moderate
Castonguay et al.	2017	+	+	+	+	+	x	Strong
Fellows et al.	2015	+	+	-	-	+	+	Strong
Hill et al.	2011	+	+	+	+	x	+	Strong
Lahousen et al.	2016	+	+	+	-	+	+	Strong
Minja et al.	2019	+	+	x	-	+	x	Moderate
Moreira & Canavarro	2010	+	+	x	+	+	+	Strong
Moreira et al.	2010	+	+	x	x	x	x	Weak
Neufeld et al.	2012	+	+	+	-	+	x	Strong
Persons et al.	2010	+	+	+	+	+	x	Strong
Pila et al.	2018	+	+	x	-	+	x	Moderate

Sikkema et al.	2009	+	+	+	+	+	+	Strong
Taal & Faber	1998	+	x	+	+	x	+	Moderate
Trindade et al.(a)	2018	x	x	x	+	+	+	Moderate
Trindade et al. (b)	2018	x	+	x	+	+	+	Moderate
Trindade et al.	2017	x	+	x	+	x	+	Moderate
Trindade et al.	2019	+	+	+	+	+	+	Strong
Trindade et al.(c)	2018	+	+	x	+	+	+	Moderate
Trindade et al.	2020	x	+	x	+	+	x	Moderate
Trindade et al.(d)	2018	x	+	x	+	x	+	Moderate
Vincent et al.	2017	x	x	+	+	+	x	Moderate

^ Key: x = not evident from article, - = not applicable to study, + = criteria met, weak = 0-33.9% criteria met, moderate = 34-66.9% criteria met, strong = 67-100% criteria met.

Discussion

This review aimed to understand the prevalence of illness related shame across long term health conditions and if there are consistently associated biopsychosocial factors. The findings indicate that shame related specifically to being diagnosed and living with a LTC has not been measured extensively or across a wide variety of physical health conditions. The majority of articles identified were in Breast Cancer, IBD and HIV populations. Whilst a small range of illness groups, they are diverse with regards to onset, treatment and symptom burden. The presence of IRS in each group begins to indicate it may be transdiagnostic factor across physical health groups. This draws parallels to the transdiagnostic nature of shame across mental health difficulties. No studies interpreted the scores of IRS with regards to a high or low level. Without further explanation or analysis of the scores reported, it is not possible to comprehensively ascertain that the experience of illness-related shame is significant or meaningful for the populations studied, or whether the experience varies by population group.

With regards to factors related to IRS, few direct contributing factors were explored. Body weight, body dissatisfaction and socialisation to gender roles were each identified in one study. Illness (IBD) symptoms were positively associated with IRS in two studies. However, it is unclear if individuals may have been able to participate in both of these studies as recruitment was by the same research group in the same geographical area. IRS was demonstrated to directly impact upon cognitive fusion, depression, self-judgement and psychological health with moderate to large effect sizes. These effects were from a range of studies with moderate to high quality.

IRS was found to be associated with 22 different variables. Broadly these can be categorised as illness-related, functional, cognitive and psychological. There was significant heterogeneity in the variables studied alongside IRS. Many similar concepts were labelled with different terms across studies e.g. psychological health, emotional wellbeing and psychological quality of life. Anxiety and depression were measured and reported by multiple studies, with consistent positive associations reported; as IRS increased so too did psychological distress.

Due to the use of predominately correlational analysis, few conclusions can be drawn about the directional relationship of illness-related shame to outcomes of psychological wellbeing (anxiety, depression, HRQoL) or functioning (cognitive, physical, social). Where analysis has allowed modelling of the direction and size of relationships, the most consistently demonstrated were depression, cognitive fusion, loneliness, experiential avoidance, and psychological quality of life. A direct relationship was also reported to increased risky behaviours i.e. unprotected sex, in one study (Sikkema et al., 2009).

There were also limitations with some of the measures used throughout studies. The WEB-SG only accounts for weight and visible symptoms of illness in the body, not enquiring about other symptoms that may be present (Castonguay et al., 2017). The HARSI was originally validated for use in comorbid CSA & HIV. This limits the external validity of using one subscale for comparison and generalisation to wider HIV population without the experience of CSA. The CISS provides a robust measure of IRS and demonstrated similar results across illness populations. However, no normative data for the CISS full scale was available, limiting its use in the comparison within or across population groups.

It is worth noting that the perception of shame varies across cultures, perceived as a predominately negative emotion in individualist cultures and associated with significant psychological and behavioural dysfunction. However, collectivist cultures advocate for shame as a means to promote group cohesion or as a positive moral aspect (Yakeley, 2018). This perception of shame has been shown to motivate behaviour and sense of self differently across cultures (Tracy et al., 2007). None of the articles identified in this review were from such collectivist cultures and so an understanding of whether illness related shame is prevalent or is associated with similar variables in these cultures cannot be drawn. Further bias in the literature is evident with one-third of identified articles from the same research group in Portugal. It cannot readily be known if scores from these studies are representative of wider European populations.

Clinical Implications

The finding that illness related shame is present across a variety of conditions and associated with psychological distress indicates the potential benefit of targeting shame in psychological interventions and ensuring it is included in assessments of wellbeing.

This supports the theoretical underpinnings and framework of Compassion Focussed Therapy (CFT, (Gilbert, 2014)). CFT postulates that the presence of illness or need to confront illness provokes shame, which in turn triggers self-critical thoughts and the threat component of the emotion regulation system (Gilbert & McEwan, 2008). Using a CFT model to overcome shame and foster compassion could in principle promote engagement in tasks of physical self-management and activate the soothing component of the emotional regulation system in order to foster warmth and safety. A recent systematic review (Austin et al., 2020) supported the use of compassion-based interventions within physical health groups. These have varied in content, length and format however, have been shown to be effective in improving anxiety, depression, improved emotion regulation and reduced feelings of isolation (Austin et al., 2020). Half the studies identified by Austin et al. (2020) tailored the content to the health population. Further clarification of transdiagnostic factors such as IRS would aid clinical decision making regarding tailored versus general intervention plans. This review's findings of IRS begin to reinforce the underpinnings of why such interventions are growing in popularity and demonstrating positive outcomes.

The associations of cognitive fusion and experiential avoidance being studied by the research group in Portugal begin to imply an Acceptance and Commitment Therapy (ACT) based approach could also be beneficial, fitting with the hexaflex model of psychological flexibility (Hayes et al., 2006). This is an area that needs further analysis, as only one paper to date has made this association between IRS and experiential avoidance. However, replications of the association with cognitive fusion is in line with a large field of research indicating ACT to be beneficial in reducing distress and improving quality of life across LTC populations (A-Tjak et al., 2015). The relevance of

these factors in combination with shame integrates concepts of compassion with ACT, such an integration has previously been discussed by Tirch et al. (2014).

From a service provision perspective, the presence of shame related to illness across varied population groups has implications for health care providers. Understanding the patients' discomfort in engaging in their illness emphasises the need for compassionate healthcare. This should aim to put individuals at ease to allow engagement with the service, whilst also modelling the strength, warmth, wisdom and non-judgment key to fostering compassion (Firth-Cozens & Cornwell, 2009). Links to behaviour such as unprotected sex and non-adherence to medical regimen indicate those with increased IRS may be at risk of social or further physical harm. These associations require further evidence in order to make generalisations across health populations, and to identify a level of distress at which individuals may be at risk. However, the identification of shame within services and appropriate intervention may provide the opportunity to reduce future harm.

Limitations

This article provides a review specifically of illness related shame in LTC's. Papers excluded for use of a global shame measure may also be relevant to drawing clinical implications. On review of search result titles there were also a significant number of qualitative articles exploring the experience of shame in various chronic illness populations. These again may be of use for those providing clinical intervention or further understanding the implications of feeling ashamed about living with one or multiple LTCs.

There are limitations to the QATSO tool used to review bias. It is designed as a brief measure of bias touching on the main areas of internal and external validity, reporting bias and confounding variables. Like all quality and risk of bias tools it may oversimplify and generalise information. Quantifying results on such measures gives the assumption that each item is equally weighted which may not be the case depending upon the research question. Here the tool has been used to give broad commentary on overall quality and to allow confidence in a narrative summary of results.

Future research and recommendations

Five of the twenty papers reported results in a format that allowed comparison to the measures' initial validation articles. Seven studies used a measure which did not have normative data published. It was beyond the scope of this article to quantitatively compare data sets, however, meta-analysis may be possible. It may also be feasible to incorporate articles which have used a global measure of shame. This paper aimed to explore the experience of shame specifically relating to living with a LTC, however, it would be clinically relevant to understand if levels of global shame are higher in LTC populations than the general population. Twenty-six articles were excluded based on use of a global measure of shame, these references are provided in appendix one.

Further high-quality research is needed within the field in order to further understand whether this is a relevant issue across physical health conditions. With increasing evidence for transdiagnostic variables involved in the distress of those living with LTCs it is recommended to use a measure of IRS that is applicable across health conditions. Review indicates that the use of CFT is efficacious in LTCs (Austin et al., 2020), the next steps with regards to IRS would be to determine its role as a mechanism in these interventions. Potential relationships to explore include whether CFT interventions work by reducing IRS, whether this is direct or mediated by any of the factors highlighted by this review e.g. experiential avoidance and cognitive fusion. Alternatively, it could be explored whether IRS moderates change in psychological distress through changes in self-compassion or behavioural change. Initially this could be scoped through single-case experimental design prior to RCTs and mediation trials.

Conclusion

The literature available to date demonstrates the presence of IRS, which has implications for health care providers in their approach and interventions in chronic illness populations. The current literature base, however, does not allow conclusions to be drawn about the prevalence of IRS or

compare levels of IRS across physical health conditions. Whilst there are limitations to the literature available, important biopsychosocial associations of IRS are indicated which would also be appropriate targets for third-wave psychological therapy. Further research is needed to progress the current understanding of IRS's role in both psychological distress and LTC self-management.

References

A-Tjak, J., Davis, M., Morina, N., Powers, M., Smits J, & Emmelkamp, P. (2015). A Meta-Analysis of the Efficacy of Acceptance and Commitment Therapy for Clinically Relevant Mental and Physical Health Problems. *Psychotherapy and Psychosomatics*, *84*, 30–36. https://doi.org/10.1159/000365764

Andrews, B., Qian, M., & Valentine, J. D. (2002). Predicting depressive symptoms with a new measure of shame: The Experience of Shame Scale. *British Journal of Clinical Psychology*, *41*(1), 29–42. https://doi.org/10.1348/014466502163778

Austin, J., Drossaert, C. H. C., Schroevers, M. J., Sanderman, R., Kirby, J. N., & Bohlmeijer, E. T. (2020). Compassion-based interventions for people with long-term physical conditions: a mixed methods systematic review. *Psychology & Health*, 1–27. https://doi.org/10.1080/08870446.2019.1699090

Baumeister, R. F., & Leary, M. R. (1995). The Need to Belong: Desire for Interpersonal Attachments as a Fundamental Human Motivation. *Psychological Bulletin*, *117*(3), 497–529. https://doi.org/10.1037/0033-2909.117.3.497

Baumeister, R. F., Stillwell, A. M., & Heatherton, T. F. (1994). Guilt: An interpersonal approach. *Psychological Bulletin*, *115*(2), 243–267. https://doi.org/10.1037/0033-2909.115.2.243

Birchwood, M., Jackson, C., Brunet, K., Holden, J., & Barton, K. (2012). Personal beliefs about illness questionnaire-revised (PBIQ-R): Reliability and validation in a first episode sample. *British Journal of Clinical Psychology*, *51*(4), 448–458. https://doi.org/10.1111/j.2044-8260.2012.02040.x

Boquiren, V. M., Esplen, M. J., Wong, J., Toner, B., & Warner, E. (2013). Exploring the influence of gender-role socialization and objectified body consciousness on body image disturbance in breast cancer survivors. *Psycho-Oncology*, *22*(10), n/a-n/a. https://doi.org/10.1002/pon.3271

Casati, J., Toner, B. B., De Rooy, E. C., Drossman, D. A., & Maunder, R. G. (2000). Concerns of patients with inflammatory bowel disease: A review of emerging themes. *Digestive Diseases and*

Sciences. Springer. https://doi.org/10.1023/A:1005492806777

Castonguay, A. L., Wrosch, C., Pila, E., & Sabiston, C. M. (2017). Body-related shame and guilt predict physical activity in breast cancer survivors over time. *Oncology Nursing Forum*, *44*(4), 465–475. https://doi.org/10.1188/17.ONF.465-475

Clark, A. (2012). Working with guilt and shame . *Advances in Psychiatric Treatment*, *18*, 137–143. https://doi.org/10.1192/apt.bp.110.008326

Conradt, M., Dierk, J.-M., Schlumberger, P., Rauh, E., Hebebrand, J., & Rief, W. (2007a). Development of the Weight- and Body-Related Shame and Guilt Scale (WEB–SG) in a Nonclinical Sample of Obese Individuals. *Journal of Personality Assessment*, *88*(3), 317–327. https://doi.org/10.1080/00223890701331856

Conradt, M., Dierk, J. M., Schlumberger, P., Rauh, E., Hebebrand, J., & Rief, W. (2007b). Development of the weight- and body-related shame and guilt scale (WEB-SG) in a nonclinical sample of obese individuals. *Journal of Personality Assessment*, *88*(3), 317–327. https://doi.org/10.1080/00223890701331856

Davids, E. ., & Roman, N. . (2014). A systematic review of the relationship between parenting styles and children's physical activity. *African Journal for Physical Health Education*, *20*(2), 228–246.

Dolezal, L., & Lyons, B. (2017). Health-related shame: An affective determinant of health? *Medical Humanities*, *43*(4), 257–263. https://doi.org/10.1136/medhum-2017-011186

Dunkley, D. M., Schwartzman, D., Looper, K. J., Sigal, J. J., Pierre, A., & Kotowycz, M. A. (2012). Perfectionism dimensions and dependency in relation to personality vulnerability and psychosocial adjustment in patients with coronary artery disease. *Journal of Clinical Psychology in Medical Settings*, *19*(2), 211–223. https://doi.org/10.1007/s10880-011-9271-2

Fellows, J. L., Flower, L., Blakey, J., Kurukulaaratchy, R., Howard, R., & Mansur, A. (2015). Case series: The application of "third wave" cognitive behavioural therapies in difficult to treat asthma. *Journal of Asthma*. https://doi.org/10.3109/02770903.2014.1003155

Firth-Cozens, J., & Cornwell, J. (2009). *The point of care: Enabling compassionate care in acute*

hospital settings. London.

Gilbert, P., Durrant, R., & McEwan, K. (2006). Investigating relationships between perfectionism, forms and functions of self-criticism, and sensitivity to put-down. *Personality and Individual Differences*, *41*(7), 1299–1308. https://doi.org/10.1016/j.paid.2006.05.004

Gilbert, P, & Andrews, B. (1998). *Shame: Interpersonal Behavior, Psychopathology, and Culture*. Oxford University Press.

Gilbert, P, & Miles, J. (2014). *Body Shame: Conceptualisation, Research and Treatment*. London: Routledge.

Gilbert, P. (1997). The evolution of social attractiveness and its role in shame, humiliation, guilt and therapy. *British Journal of Medical Psychology*, *70*(2), 113–147. https://doi.org/10.1111/j.2044-8341.1997.tb01893.x

Gilbert, P. (2000). The relationship of shame, social anxiety and depression: the role of the evaluation of social rank. *Clinical Psychology & Psychotherapy*, *7*(3), 174–189. https://doi.org/10.1002/1099-0879(200007)7:3<174::AID-CPP236>3.0.CO;2-U

Gilbert, P. (2014). The origins and nature of compassion focused therapy. *British Journal of Clinical Psychology*, *53*(1), 6–41. https://doi.org/10.1111/bjc.12043

Gilbert, P, & Procter, S. (2006). Compassionate mind training for people with high shame and self-criticism: overview and pilot study of a group therapy approach. *Clinical Psychology & Psychotherapy*, *13*(6), 353–379. https://doi.org/10.1002/cpp.507

Harandi, T. F., Taghinasab, M. M., & Nayeri, T. D. (2017). The correlation of social support with mental health: A meta-analysis. *Electronic Physician*, *9*(9), 5212–5222. https://doi.org/10.19082/5212

Harder, D. W., Cutler, L., & Rockart, L. (1992). Assessment of Shame and Guilt and Their Relationships to Psychopathology. *Journal of Personality Assessment*, *59*(3), 584–604. https://doi.org/10.1207/s15327752jpa5903_12

Hayes, S. C., Luoma, J. B., Bond, F. W., Masuda, A., & Lillis, J. (2006). Acceptance and Commitment

Therapy: Model, processes and outcomes . *Behaviour Research and Therapy*, 44(1), 1–25.

Hill, J., Holcombe, C., Clark, L., Boothby, M. R. K., Hincks, A., Fisher, J., … Salmon, P. (2011). Predictors of onset of depression and anxiety in the year after diagnosis of breast cancer. *Psychological Medicine*, *41*(7), 1429–1436. https://doi.org/10.1017/S0033291710001868

Hutchinson, P., & Dhairyawan, R. (2017). Shame, stigma, HIV: Philosophical reflections. *Medical Humanities*, *43*(4), 225–230. https://doi.org/10.1136/medhum-2016-011179

Hyphantis, T., Goulia, P., & Carvalho, A. F. (2013). Personality traits, defense mechanisms and hostility features associated with somatic symptom severity in both health and disease. *Journal of Psychosomatic Research*, *75*(4), 362–369. https://doi.org/10.1016/j.jpsychores.2013.08.014

James, K., Verplanken, B., & Rimes, K. A. (2015). Self-criticism as a mediator in the relationship between unhealthy perfectionism and distress. *Personality and Individual Differences*, *79*, 123–128. https://doi.org/10.1016/j.paid.2015.01.030

Kaufman, G. (1996). *The psychology of shame: Theory and treatment of shame-based syndromes*. Springer. https://doi.org/10.1016/s0191-8869(97)85593-6

Kim, S., Thibodeau, R., & Jorgensen, R. S. (2011). Shame, Guilt, and Depressive Symptoms: A Meta-Analytic Review. *Psychological Bulletin*, *137*(1), 68–96. https://doi.org/10.1037/a0021466

Kupfer, J., Brosig, B., Niemeier, V., & Gieler, U. (2005). Zur Validität des Hautzufriedenheitsbogens (Hautzuf)–Validity of the Touch-Shame-Disgust-Questionnaire (TSD-Q). *Psychother Psychosom Med*. *55*(02), P_078

Lahousen, T., Kupfer, J., Gieler, U., Hofer, A., Linder, M. D., & Schut, C. (2016). Differences between psoriasis patients and skin-healthy controls concerning appraisal of touching, shame and disgust. *Acta Dermato-Venereologica*, *96*, 78–82. https://doi.org/10.2340/00015555-2373

Lazare, A. (1987). Shame and Humiliation in the Medical Encounter, *Archives of internal medicine*, 147(9), 1653-1658.

McFall, L., & Johnson, V. (2009). Shame: Concept Analysis. *Journal of Theory Construction & Testing*, *13*(2), 57–63.

Mckinley, N. M., & Hyde, J. S. (1996). The Objectified Body Consciousness Scale Development and Validation. *Psychology of Women Quarterly* (Vol. 20).

Mehr, K. E., & Adams, A. C. (2016). Self-Compassion as a Mediator of Maladaptive Perfectionism and Depressive Symptoms in College Students. *Journal of College Student Psychotherapy*, *30*(2), 132–145. https://doi.org/10.1080/87568225.2016.1140991

Minja, L., Cichowitz, C., Knettel, B. A., Mahande, M. J., Kisigo, G., Knippler, E. T., … Watt, M. H. (2019). Attitudes Toward Long-Term Use of Antiretroviral Therapy Among HIV-Infected Pregnant Women in Moshi, Tanzania: A Longitudinal Study. *AIDS and Behavior*, *23*(9), 2610–2617. https://doi.org/10.1007/s10461-019-02622-5

Moreira, H., & Canavarro, M. C. (2010). A longitudinal study about the body image and psychosocial adjustment of breast cancer patients during the course of the disease. *European Journal of Oncology Nursing*, *14*(4), 263–270. https://doi.org/10.1016/j.ejon.2010.04.001

Moreira, H., Silva, S., Marques, A., & Canavarro, M. C. (2010). The Portuguese version of the Body Image Scale (BIS) - psychometric properties in a sample of breast cancer patients. *European Journal of Oncology Nursing*, *14*(2), 111–118. https://doi.org/10.1016/j.ejon.2009.09.007

Naylor, C., Parsonage, M., Mcdaid, D., Knapp, M., Fossey, M., & Galea, A. (2012). Long-term conditions and mental health The cost of co-morbidities.

Neufeld, S. A. S., Sikkema, K. J., Lee, R. S., Kochman, A., & Hansen, N. B. (2012). The Development and Psychometric Properties of the HIV and Abuse Related Shame Inventory (HARSI). *AIDS and Behavior*, *16*, 1063–1074. https://doi.org/10.1007/s10461-011-0086-9

NHS Digital. (2020). Supporting Information: Long Term Physical Health Condition. Retrieved June 26, 2020, from https://www.datadictionary.nhs.uk/data_dictionary/nhs_business_definitions/l/long_term_physical_health_condition_de.asp?shownav=1

Persons, E., Kershaw, T., Sikkema, K. J., & Hansen, N. B. (2010). The Impact of Shame on Health-Related Quality of Life Among HIV-Positive Adults with a History of Childhood Sexual Abuse.

AIDS Patient Care and STDs, *24*(9), 571–580. https://doi.org/10.1089/apc.2009.0209

Pila, E., Sabiston, C. M., Castonguay, A. L., Arbour-Nicitopoulos, K., & Taylor, V. H. (2018). Mental health consequences of weight cycling in the first-year post-treatment for breast cancer. *Psychology & Health*, *33*(8), 995–1013. https://doi.org/10.1080/08870446.2018.1453510

Roman, N. V, & Frantz, J. M. (2013). The prevalence of intimate partner violence in the family: a systematic review of the implications for adolescents in Africa. *Family practice,* 30(3), 256-265 https://doi.org/10.1093/fampra/cms084

Scottish Government. (2015). *Long Term Conditions*. Retrieved June 5, 2018, from http://www.gov.scot/Topics/Health/Services/Long-Term-Conditions

Sikkema, K. J., Hansen, N. B., Meade, C. S., Kochman, A., & Fox, A. M. (2009). Psychosocial predictors of sexual HIV transmission risk behavior among HIV-positive adults with a sexual abuse history in childhood. *Archives of Sexual Behavior*, *38*(1), 121–134. https://doi.org/10.1007/s10508-007-9238-4

Taal, L. A., & Faberb, A. W. (1998). Posttraumatic stress and maladjustment among adult burn survivors l-2 years postburn. *Burns* (Vol. 24).

Taal, L., & Faber, A. W. (1998). Posttraumatic stress and maladjustment among adult burn survivors 1 to 2 years postburn Part II: the interview data. *Burns* (Vol. 24).

Takahashi, H., Yahata, N., Koeda, M., Matsuda, T., Asai, K., Okubo, Y., & Hospital, A. (2004). Brain activation associated with evaluative processes of guilt and embarrassment: an fMRI study. https://doi.org/10.1016/j.neuroimage.2004.07.054

Tangney, J. P., Miller, R. S., Flicker, L., & Barlow, D. H. (1996). Are shame, guilt, and embarrassment distinct emotions? *Journal of Personality and Social Psychology*, *70*(6), 1256–1269. https://doi.org/10.1037//0022-3514.70.6.1256

Tirch, D., Schoendorff, B., & Silberstein, L. . (2014). *The ACT Practitioner's Guide to the Science of Compassion: Tools for fostering psychological flexibility*. New Harbringer Publications, Inc.

Tracy, J., Robins, R., & Tangney, J. (2007). *The Self-conscious Emotions: Theory and Research* .

Guildford Press.

Trindade, I. A., Duarte, J., Ferreira, C., Coutinho, M., & Pinto-Gouveia, J. (2018). The impact of illness-related shame on psychological health and social relationships: Testing a mediational model in students with chronic illness. *Clinical Psychology & Psychotherapy*, *25*(3), 408–414. https://doi.org/10.1002/cpp.2175

Trindade, I. A., Ferreira, C., & Pinto-Gouveia, J. (2017a). Chronic Illness-Related Shame: Development of a New Scale and Novel Approach for IBD Patients' Depressive Symptomatology. *Clinical Psychology and Psychotherapy*, *24*(1), 255–263. https://doi.org/10.1002/cpp.2035

Trindade, I. A., Ferreira, C., & Pinto-Gouveia, J. (2017b). Chronic Illness-Related Shame: Development of a New Scale and Novel Approach for IBD Patients' Depressive Symptomatology. *Clinical Psychology & Psychotherapy*, *24*(1), 255–263. https://doi.org/10.1002/cpp.2035

Trindade, I. A., Irons, C., Ferreira, C., Portela, F., & Pinto-Gouveia, J. (2019). The influence of self-criticism on depression symptoms among ambulatory patients with inflammatory bowel disease. *Clinical Psychology & Psychotherapy*, *26*(6), 743–750. https://doi.org/10.1002/cpp.2398

Trindade, I. A., Marta-Simões, J., Ferreira, C., & Pinto-Gouveia, J. (2018). Developments on committed action: Validity of the CAQ-8 and analysis of committed action's role in depressive symptomatology in breast cancer patients and healthy individuals. *Clinical Psychology and Psychotherapy*, *25*(1), e42–e50. https://doi.org/10.1002/cpp.2125

Trindade, I. A., Marta-Simões, J., Ferreira, C., & Pinto-Gouveia, J. (2018). Chronic illness-related cognitive fusion explains the impact of body dissatisfaction and shame on depression symptoms in breast cancer patients. *Clinical Psychology & Psychotherapy*, *25*(6), 886–893. https://doi.org/10.1002/cpp.2323

Trindade, I., Ferreira, C., & Pinto-Gouveia, J. (2017). Shame and emotion regulation in inflammatory bowel disease: Effects on psychosocial functioning., *Journal of Health Psychology,* (0) 1–11. https://doi.org/10.1177/1359105317718925

Vincent, W., Fang, X., Calabrese, S. K., Heckman, T. G., Sikkema, K. J., & Hansen, N. B. (2017). HIV-related shame and health-related quality of life among older, HIV-positive adults. *Journal of Behavioral Medicine*, *40*(3), 434–444. https://doi.org/10.1007/s10865-016-9812-0

Werner, A., Isaksen, L. W., & Malterud, K. (2004). "I am not the kind of woman who complains of everything": Illness stories on self and shame in women with chronic pain. *Social Science and Medicine*, *59*(5), 1035–1045. https://doi.org/10.1016/j.socscimed.2003.12.001

World Health Organization Regional Office for Europe (2017). *Addressing comorbidity between mental disorders and major noncommunicable diseases*.

Wiechelt, S. A. (2017). Substance Use & Misuse The Specter of Shame in Substance Misuse. *Substance Use & Misuse*, 42(2-3), 399-409. https://doi.org/10.1080/10826080601142196

Wong, W. C. W., Cheung, C. S. K., & Hart, G. J. (2008). Development of a quality assessment tool for systematic reviews of observational studies (QATSO) of HIV prevalence in men having sex with men and associated risk behaviours. *Emerging Themes in Epidemiology*. BioMed Central. https://doi.org/10.1186/1742-7622-5-23

Yakeley, J. (2018). Shame, culture and mental health. *Nordic Journal of Psychiatry*, *72*(sup1), S20–S22. https://doi.org/10.1080/08039488.2018.1525641

Group Compassion Focused Therapy for diverse physical health conditions: A multiple baseline case series

Anna Maddison[12], Dr Ellie Caldwell [2] and Dr David Gillanders [1]

[1]Clinical & Health Psychology, School of Health and Social Science, University of Edinburgh

[2] Clinical Health Psychology, NHS Lothian

Author Note:

No known conflicts of interest to disclose.

Corresponding author: Anna Maddison, S0819674@ed.ac.uk, Clinical & Health Psychology, University of Edinburgh, School of Health in Social Science, Teviot Place, Edinburgh, EH8 9AG.

Written for submission to the *Journal of Behavioral Medicine*. See appendix Six for journal submission guidelines.

Abstract

Objectives

To explore the effectiveness of a group-based compassion focussed therapy intervention for people with diverse and/or multiple long-term health conditions (LTCs).

Methods

A multiple baseline, single case experimental design was undertaken. Three daily questions were collected along with a weekly battery of measures of adjustment (psychological wellbeing, self-efficacy, social functioning, illness cognitions) and compassion. Change over time was analysed at the individual level using visual and quantitative analysis.

Results

Six individuals completed intervention and data collection. Results showed a consistent positive change in self-compassion. Participants reported a gradual pattern of therapeutic change over the course of the intervention. Measures of adjustment did not change consistently across participants.

Conclusions

A group CFT intervention was effective at improving self-compassion in individuals with diverse physical health conditions. The pattern of change where improvement was seen was gradual. Further research is needed to understand the relationship between compassion and adjustment to illness.

Keywords

Compassion Focused Therapy; Chronic Illness; Long Term Conditions; Adjustment; Multiple Baseline; Single Case Experimental Design

Acknowledgments

Greg Halliday, Assistant Psychologist, Clinical Health Psychology, NHS Lothian

Dr Audrey Matthews, Clinical Psychologist, Clinical Health Psychology, NHS Lothian

Dr Jenny Strachan, Clinical Psychologist, Clinical Health Psychology, NHS Lothian

Dr Lisa Harrow, Clinical Psychologist, Clinical Health Psychology, NHS Lothian

Group Compassion Focused Therapy for diverse physical health conditions: A multiple baseline case series

Introduction

Long Term Health Conditions (LTCs):

It is estimated approximately 15 million people in England and 2 million people in Scotland (Department of Health, 2012; Scottish Government, 2015a) are living with at least one Long Term Health Condition (LTC). This includes any condition which cannot be cured, lasts more than a year and requires ongoing management (National Institute for Health and Care Excellence, 2017); including but not limited to, heart and respiratory disease, epilepsy, cancer, HIV, persistent pain and diabetes. With advancing healthcare interventions and an ageing population this number continues to rise, meaning people are living longer with physical illness. The number of people living with and managing multiple physical health conditions is therefore, also rising.

The changing health profile of the population presents a challenge for the health care system. Estimates indicate care for LTCs presently accounts for 55% of GP appointments and 68% of outpatient and A&E appointments (Naylor et al., 2012). The increase in these populations provides the traditional health service pathways with difficulty providing streamlined and person-centred care. Increasingly, models of service provision aim to support individuals' self-management by having "people as partners". That is, committing to joint working and decision making, allocating resources responsively, and having organisational policies and processes that each individual is able to navigate (Health Care Alliance, 2018). It is recommended that services aim to treat the individual as a whole, providing coordinated care in which individuals are involved in developing care plans based around their values and needs (National Institute for Health and Care Excellence, 2017; Naylor et al., 2016).

Living with one or more LTCs involves recognition of loss; with changes commonly experienced in health status, functional ability, independence and social roles. This has implications

for a different future than the individual may have planned or expected. This is combined with the need to proactively engage in self-management tasks. The burden of illness on everyday functioning can be significant. Management of a LTC often requires a significant adaptation to lifestyle. Diet, fluid intake, physical activity, and often complex medication regimens with their own side effects need to be managed. An individual's ability to engage in occupation, education and social activities can be altered. Previously routine activity can become increasingly difficult without support from others. Psychologically, those with physical health conditions are two to three times more likely to experience mental health difficulties than the general population (Naylor et al., 2012). The number of mental health difficulties experienced increases with the number of physical health conditions. This is a bi-directional relationship in which physical illness impacts psychological wellbeing through a variety of mechanisms including: biological changes; changes to activity; social connection opportunities and; cognitions surrounding illness and the self (Chida et al., 2008; Ohrnberger et al., 2017; Renn et al., 2011). Mental health difficulties such as depression and anxiety reduce the ability to engage in self-management, increasing vulnerability to further physical ill health. Mental health difficulties in LTC groups are also more common in more socially and economically deprived individuals (Barnett et al., 2012). These individuals are often less able to engage in the health care system and experience a lower level of health literacy which hinders the ability for self-management (Lastrucci et al., 2019).

Adjustment to illness:

Adjustment is the term most commonly coined to denote a process of psychologically, socially and physically adapting to and successfully living with illness. This process leads to less interference of illness on life roles and relationships, less psychological distress and good illness management (de Ridder et al., 2008; Moss-Morris, 2013). Whilst many theories have been developed to explain this process the most recent is that of Moss-Morris (Moss-Morris, 2013). This 'Unified Theory' draws together background factors e.g. early life experience, personality traits,

availability of health and social care, with illness factors e.g. symptoms, certainty, prognosis. These factors interact with critical events e.g. diagnosis, relapse or change in life roles, and with ongoing stressors such as managing relationships, lifestyle changes, medical regimen and altered physical limits. The model makes clear the many facets of adjustment and allows the identification of areas in which an individual may be struggling, including the cognitive and behavioural factors that may be involved. Importantly, poor adjustment does not always equate to a distinct psychopathology, although it can present comorbidly (Sharpe & Curran, 2006).

Alongside the presentation of depression, anxiety and heightened distress, in clinical practice poor adjustment is often observed through difficulties with medical self-management and disproportionate distress or disturbance to roles and relationships. Further cognitive factors can include: high perceived stress; wishful thinking; dysfunctional or unhelpful cognitive styles (Moss-Morris, 2013).

With recognition of the role of psychological factors in physical health conditions increasing, researchers have aimed to identify these factors in greater detail. One proposed mediating factor between illness and psychological distress is the presence of increased shame and self-criticism. High levels of both have been found across LTC populations (Campos et al., 2012; Rudich et al., 2008). Illness-related shame specifically pertains to how the diagnosis and symptoms of illness negatively impact the individual's sense of self and subsequent behaviours. It has been associated with anxiety, depression and poorer physical, social and psychological wellbeing (Maddison et al., 2020). Conversely, the presence of compassion has been demonstrated to mediate the relationship with psychological distress and to be positively associated with adjustment to illness (Clegg et al, 2019; Sirois et al., 2016; Wren et al., 2012). In particular increased compassion has been linked to adaptive coping mechanisms and practicing health promoting behaviours (Sirois et al., 2015).

The role of Psychology:

The role for psychology in physical health services has been well evidenced (Naylor et al., 2016; Royal College of Psychiatrists, 2013). Psychological interventions can facilitate a reduction in distress, managing new or chronic mental health difficulties, increasing self-management behaviours, engaging in relationships with health providers and, managing communication and relationships. They can also facilitate a psychosocial understanding of patient behaviour and distress within staff teams, providing training to disseminate a psychological and holistic approach to patients. To date, interventions based upon psychological theory have predominately been delivered through a cognitive-behavioural model. This approach is well evidenced with high quality research and recommended by national governing bodies (Scottish Government, 2015b). There is currently less evidence across other psychological modalities where the breadth and depth of research has not yet reached threshold for such interventions to be recommended at national policy level.

Compassion Focussed Therapy (CFT) is one modality in which the evidence base is developing. Increasingly CFT based interventions are being developed and evidenced as efficacious in physical health populations (Austin et al., 2020). CFT has routes in Buddhist, evolutionary and social psychology. As a third-wave psychological therapy it is based around cognitive and behavioural intervention strategies. It differs in bringing an evolutionary approach and understanding to distress. It understands distress as a commonality within humanity, which is inherent in having brains which have maintained basic survival instincts whilst continuing to develop advanced cognitive skills. Targeting compassion through recognising why we feel threat, and activating the soothing emotion regulation system has been shown to reduce shame and self-criticism, increasing psychological wellbeing (Gilbert & Procter, 2006).

Interventions used within LTC populations have ranged from comprehensive interventions of CFT to single strategy brief interventions. In a recent review of the literature (Austin et al., 2020) eleven group interventions were found. All interventions were delivered to a specific LTC population. Overall interventions were acceptable to the population groups and saw improvements in anxiety, depression, self-compassion and health-related quality of life (Austin et al., 2020).

This Study – Rebalance:

In line with evidence regarding multimorbidity and the role of transdiagnostic psychological mechanisms involved in distress and poor adjustment across physical health groups, the Rebalance group intervention was developed. This is a ten-session structured group programme aiming to increase adjustment to illness, via increasing self-compassion. The group was available to individuals with any and/or multiple physical health conditions following assessment within the Clinical Health Psychology service. The group ran weekly for 2.5 hours, facilitated by two Clinical Psychologists. A group intervention was chosen as the format provides a space for sharing experiences and peer support which may not be otherwise available to individuals (Yalom & Leszcz, 2005). Third wave therapies have previously been shown to be efficacious in mixed health condition groups (Brassington et al., 2016). This group represented a novel CFT intervention in mixing individuals with diverse LTCs.

Evaluating new interventions – Single Case Experimental Design (SCED)

When developing novel interventions it is vital to understand how the intervention works; it's process, outcomes and applicability to the desired population. Single Case Experimental Design (SCED) is a within-subjects design which allows for this level of evaluation. SCED has been used widely in the development and evaluation of interventions designed to impact human behaviour (Kazdin, 2016). Within Clinical Psychology the use of SCED became popular with the rise in behavioural approaches in the 1960s (Baer et al., 1987). They are now more commonly used in the fields of Challenging Behaviour and physical rehabilitation where observable, quantifiable measurements can be taken by the researcher. There is however, a growing interest to use SCED within Clinical Psychology interventions as a means of understanding and evaluating change at the individual client level (Kazdin, 2019).

Aims:

- To test the individual effectiveness of Rebalance, a CFT group intervention for people with various and/or multiple long-term health conditions, in promoting positive adjustment to LTC.
- To track individual change across time to identify any patterns, similarities or differences in participants response throughout the intervention.

Method

Design

A concurrent multiple baseline (MB), single case experimental design (SCED) was employed. Repeated daily measures were obtained over a six to ten-day baseline phase (A), when no treatment was provided. Subsequently, repeated daily and weekly measures were obtained over a ten-session treatment phase lasting 11-13 weeks (B).

Multiple baseline design was used in order to demonstrate stability over participants prior to intervention, without the increased demand of prolonged data collection in a clinical sample. Systematic replication was achieved through additional participants and varied group facilitators in order to strengthen generality of findings. MB design relies a variety of baseline lengths in order to gain stable baseline scores prior to commencing intervention. This allows change to be attributable to the intervention and not extraneous variables. Traditionally this results in interventions commencing at different time points for individuals; this study chose to commence baselines at different points, with the intervention onset required to be simultaneous for the group.

The study was approved by the East of Scotland Regional Ethics Committee II (REC reference number: 18/SS/0164) and registered on clinicaltrails.gov.uk, identification number NCT04040972.

Participant exclusion and inclusion criteria:

All participants gave written informed consent to participate and for their electronic health record to be accessed. Only individuals who were assessed by Clinical Health Psychology and

referred to the service's Rebalance group were eligible. The group's inclusion criteria were: experiencing difficulties adjusting to one or more chronic physical health condition(s); willing and motivated to attend a group facilitated in English; exhibit sufficient interpersonal skills and impulse control to allow engagement with group members without disrupting group dynamics and; capacity to provide informed consent.

Exclusion criteria were: moderate or severe impairment of cognitive function; primary problem related to substance misuse; actively suicidal or experiencing an acute deterioration in mental health including experiencing an acute psychotic episode.

Materials:

Fives scales were included in the weekly battery to represent compassion and factors commonly associated with adjustment to living with a LTC. These were:

- *Compassionate Engagement and Actions Scale* (CEAS; (Gilbert et al., 2017): 39 items covering three flows of compassion. Individual scales are provided for: self-compassion; compassion to others and; compassion from others. Each scale is comprised of two domains, engagement and action. Higher scores indicate higher perceived availability of compassion. All subscales have high internal consistency with Cronbach's alpha scores between .74 to .94 (Lindsey, 2017).
- *Illness Cognitions Questionnaire (ICQ;* (Evers et al., 2001): 18 items rated on a four-point scale. Assesses three subscales of cognitive styles: helplessness, acceptance and perceived benefits. Each scale demonstrated high internal consistency (Cronbach's alpha >0.81). Each subscale is scored from 6 – 24 with lower scores of acceptance and perceived benefits and higher scores of helplessness indicating less adaptive cognition around illness.
- *The Warwick-Edinburgh Mental Well-being scale* (*WEMWBS*; (Tennant et al., 2007): A 14 item measure of psychological wellbeing covering both emotional and functional aspects of wellbeing. Demonstrates high internal consistency (alpha level 0.91). A license was gained to

use the tool. Scores can be categorised as high (60-70), average (43-59) and low (14-42). Minimally important change has been estimated between three and eight points.

- *Work and Social adjustment scale (WASA*; (Mundt et al., 2002): A 5-item measure of functional impairment due to a specified stressor with good internal consistency (range: 0.70-0.94). Scores range from 0 – 40 with higher scores indicating more perceived impairment to functioning.
- *Self- efficacy for managing chronic disease scale* (SE; (Lorig et al., 2001). A 6-item measure of perceived self-efficacy to manage chronic illness. Validated within a variety of long-term condition populations (alpha level of .91) and demonstrated to be sensitive to change (Ritter & Lorig, 2014). Scored 1-10 with a mean score; higher scores indicating better perceived self-efficacy.

The three daily questions were developed in collaboration with group facilitators and a previous Rebalance group cohort towards the end of their group programme. They expressed the need to consider adjustment to the physical and psychological consequences of their illness separately. Semantics were discussed within the group e.g. use of 'psychological' vs 'emotional', and 'impact' vs 'consequences'. The final questions were:

- How well do you feel you are dealing with the emotional consequences of your health condition today?
- How well do you feel you are dealing with the physical consequences of your health condition today?
- How able do you feel to talk to yourself with wisdom, strength, warmth and non-judgment today?

Each of the questions were answered on a 5-point Likert scale labelled: very poorly, poorly, okay, well, very well. These were ranked 1-5 respectively, with higher scores indicating better self-reported adjustment or compassion.

Intervention

The content and structure of Rebalance was developed iteratively over four initial cohorts. This project reported cohorts five and six which adhered to the same format and structure. Each week the group covered a new knowledge point and a new skill; gradually increasing understanding of compassion and developing mindfulness and compassion-based practices (schedule in table one). As an interactive, therapeutic group, individuals were encouraged to engage in small and large group discussions and exercises.

Table One: Rebalance ten-week programme

Week	*Ideas introduced*	*Tools practiced*
1	Introducing compassion	Grounding Distraction with planned 'thinking time'
2	Adjustment process Three circles model	Soothing rhythm breathing Soothing activities
3	Tricky human brains Flexibility of attention	Paying attention without judgement (mindfulness) Paying attention to the body with compassion
4	Individual review	Checking progress and understanding Troubleshooting difficulties and barriers Consolidating value driven goals
5	Understanding emotions	Acknowledging and allowing emotions Taking a break from distress: Calm place imagery
6	Compassion: self to others Versions of self How we affect others' systems	Developing compassion Compassionate communication
7	Compassion: others to self Responding to the inner critic Allowing compassion in	Developing a perfect compassionate other Eliciting, noticing and allowing compassion from others
8	Compassion: self to self Valuing self-compassion 'Fake it til you make it'	Developing a self-compassionate voice Making self-compassionate choices
9	Understanding change	Planning for the future
10	Individual review	Feedback on progress and intervention How to maintain progress

Three participants attended cohort five and three attended cohort six. Due to public holidays there was a period of two weeks with no input for the first cohort and three weeks for the second. Three main facilitators were involved in the groups with one involved in both groups, and a fourth providing service cover. Fidelity to intervention was ensured through facilitators meeting prior to each week's group to discuss the session content. Facilitators were qualified Clinical Psychologists with training in CFT.

Data analysis

All data was plotted using Microsoft Excel. Visual analysis was undertaken according to guidelines proposed by Lane and Gast (2014). Characteristics within and between phases included: the trend and level of data; the degree of the slope which reflects strength of change in trend and; change in variability of the data, reflecting stability of the characteristic. The split middle method was used to bolster this, providing median scores across quartile ranges of the intervention to clarify judgement made visually.

A tau-u statistic was calculated for daily questions using an online calculator available at singlecaseresearch.org (Vannest et al., 2016). This provided an analysis of baseline trend and a measure of overall concordance or discordance between phases alongside a significance level (Brossart et al., 2018; Parker et al., 2011). This calculation has shown similar distributions to other commonly used statistics in SCED however, to date no gold standard calculation has been chosen in the field (Parker et al., 2011).

The weekly battery scores were compared from baseline to end of intervention through calculation of a reliable change index (RCI) and Clinically Significant Change (CSC). The Leeds Reliable Change Index Calculator (LRCIC; Agostinis, 2007; Morley and Dowzer, 2014) was used which is based upon the Jacobson and Traux calculation (1991). The LRCIC is an automated file in which pre- and post- intervention scores and normative data (Cronbach's α, mean, and SD) for clinical and normative samples are entered and RCI figures are then provided. This allows for the categorisation

of recovered (passed both CSC normative and RCI criteria), Improved (passed RCI criteria alone), Unchanged (passed neither), or Deteriorated (passed RCI in the negative direction). Criteria for determining a cut score for CSC are described by Jacobson and Truax (Jacobson & Truax, 1991). Here criteria C is used where normative data is available (CEAS, Gilbert et al., 2017; WEMWBS, Tennant et al, 2007), requiring scores post intervention to fall within 2 standard deviations of the normative sample mean. Criteria A is used where measures pertain specifically to an illness experience and normative data was not available (WASA, SE, ICQ), requiring an improvement of 2 standard deviations from the clinical population mean.

Results

Participants

Twelve participants consented to participate over two groups. Six participants subsequently did not attend or dropped out of the Rebalance group without enough data for inclusion. Five women and one man completed the intervention (mean age 36, range 18-46). This ratio is representative of those attending the group where the percentage of men was 17.5% over six cohorts. No participants had experience of the same primary physical health diagnosis although the experience of persistent pain was common.

Table Two: Participant demographics

Participant	*Age range*	*Gender*	*Health Conditions*	*Previous psychological input*	*Sessions attended*	*Baseline length*
1	25-35	Female	Polycystic Ovaries Syndrome, Pelvic Pain, Obesity, Endometriosis, Arthritis,	Five episodes with adult mental health services. Ongoing medication review. Reported anxiety disorder.	80%	10 days
2	18-25	Female	Idiopathic Pulmonary Arterial Hypertension	One episode with paediatric psychology	60%	9 days
3	45-55	Female	Slow bowel, Arthritis, Chronic Pain	One episode with clinical health psychology	100%	6 days
4	45-55	Female	Genetic disorder, Chronic Pain, Endometriosis	One episode with clinical health psychology. Reported anxiety disorder.	60%	10 days
5	45-55	Male	Neuropathic chronic pain, Tinnitus	One episode of depression.	100%	9 days
6	18-25	Female	Ulcerative Colitis	None	70%	7 days

Daily measures:

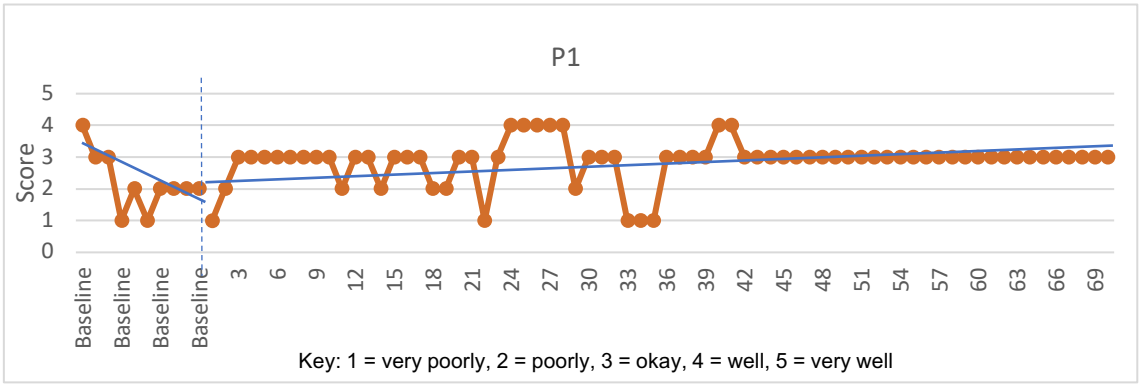
Question: *How well do you feel you are dealing with the emotional consequences of your health condition today?*

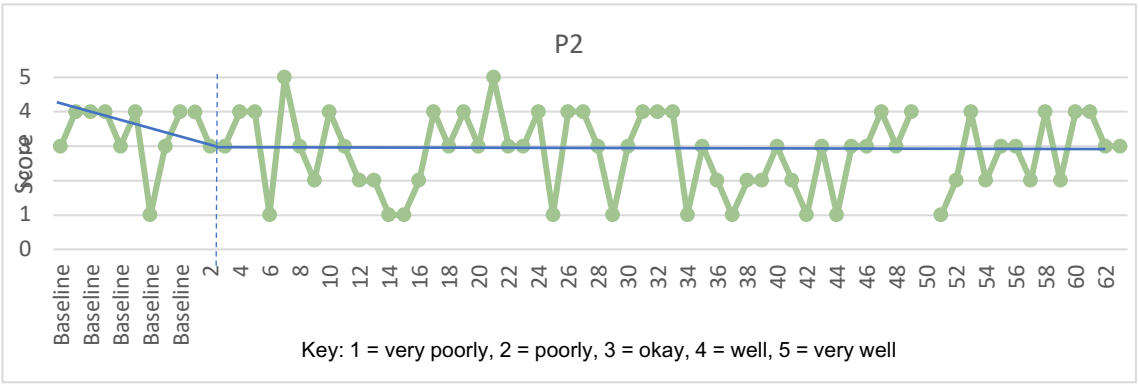
Baseline. Three participants reported a decreasing worsening trend over baseline (1, 2, 6). Participant 4 reported an increasing baseline trend while two participants (3 & 5) reported a stable baseline level.

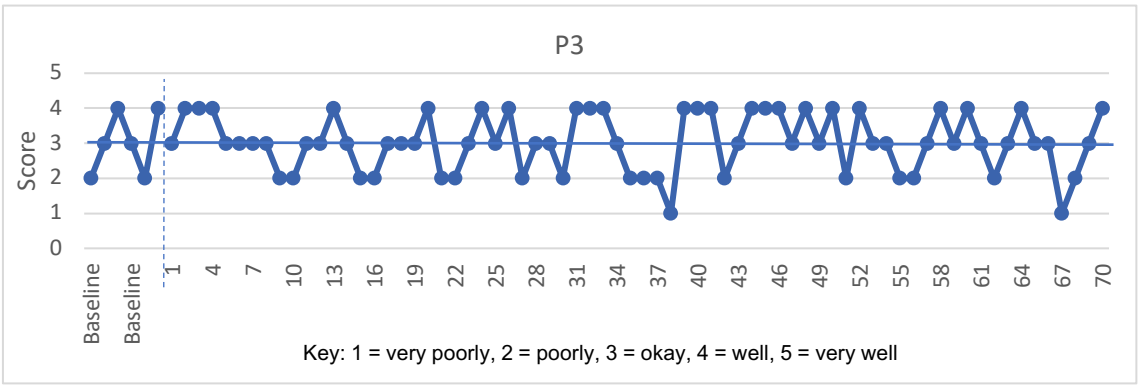
Intervention. Three participants demonstrated a significant therapeutic change in level or trend over the course of the intervention (1: tau-U = 0.47, *p <0.05, 90%* CI 0.147-0.793; 4: tau-U = 0.577, p<.05, 90% CI 0.253-0.902; 6: tau-U = 0.5343, *p*=0.05*,* CI 90% 0.157-0.911). Three participants did not demonstrate significant change (2: tau-U = -0.276, *p*=0.183*,* CI 90% -0.617-0.065; 3: tau-U = -

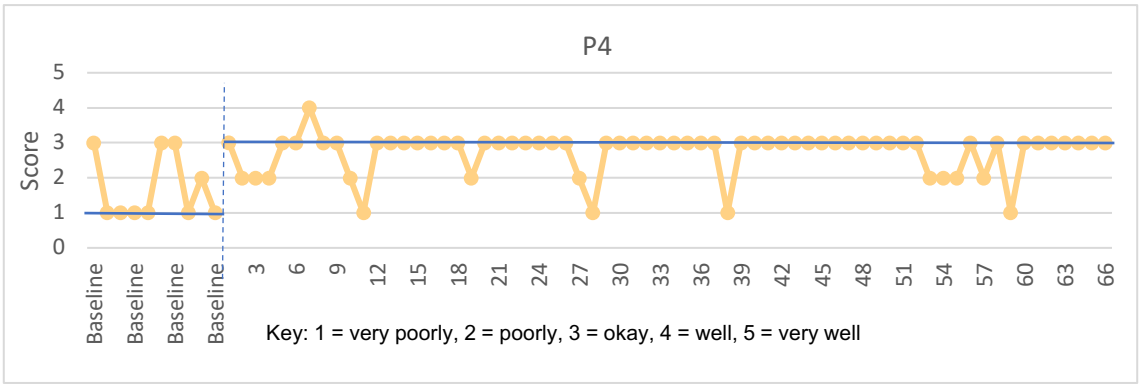
0.3024, *p*=0.221, CI 90% -0.709-0.104; 5: tau-U = 0.159, *p*=0.445, CI 90% -0.185-0.504). Visual analysis (see figure 1) indicated no trend for participants 2, 3, 4 and 5. A change in level was observed from the beginning of the intervention for participant four. Both participants one and six reported a decreasing tend in baseline and increasing trend over intervention with increasing stability in the latter half of the intervention phase. Overall change across participants was significant: tau-U = 0.255, *p<0.5*, 95% CI = 0.083-0.428

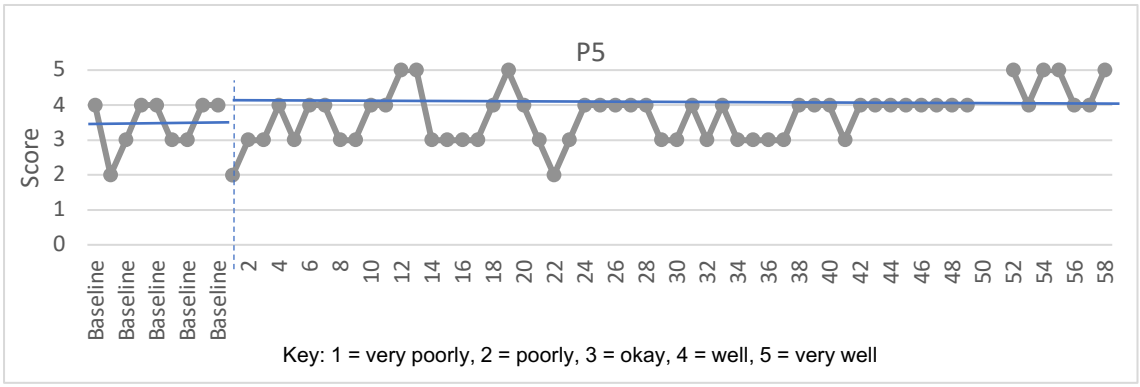
Figure One: Responses to daily question "*How well do you feel you are dealing with the emotional consequences of your health condition today?*

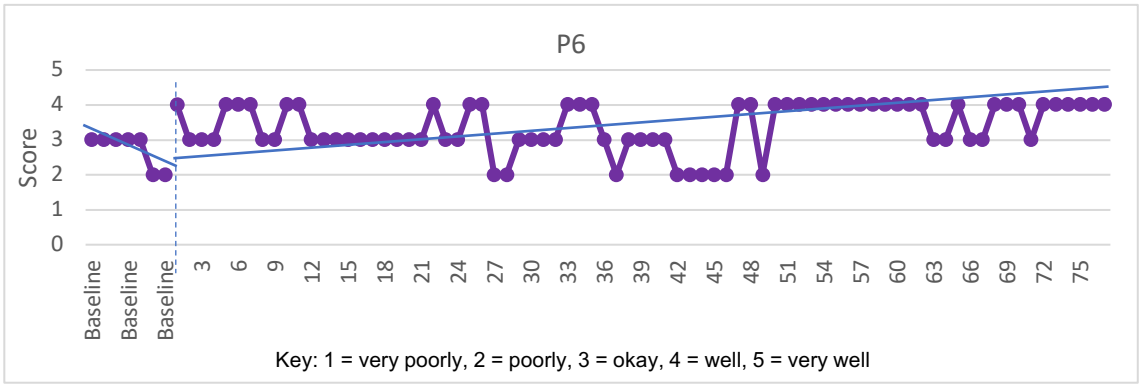












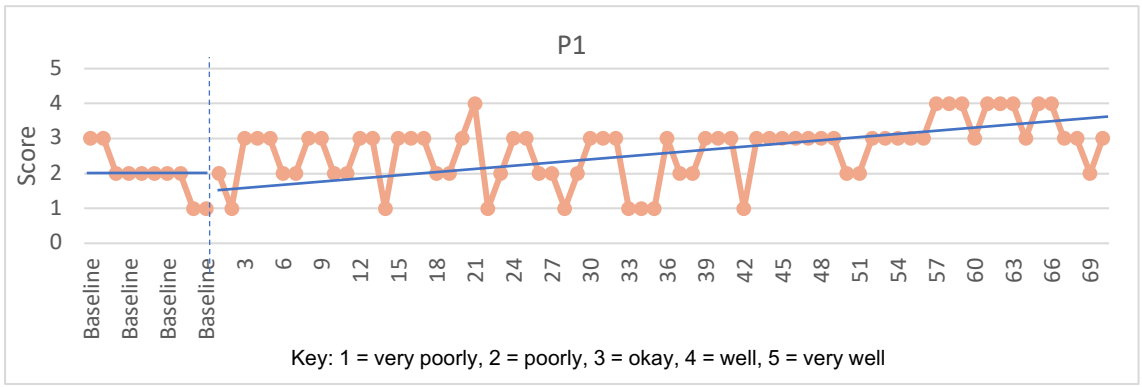
Question: *How well do you feel you are dealing with the physical consequences of your health condition today?*

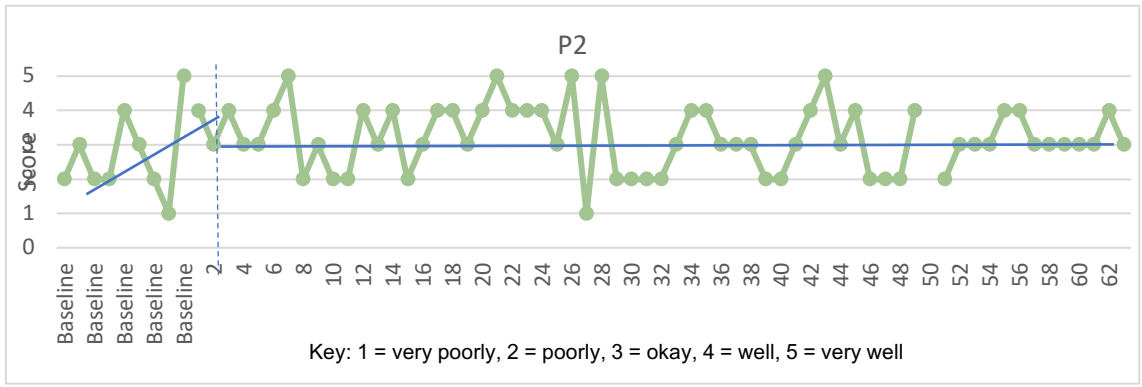
Baseline. By visual analysis five participants reported a stable baseline. Participant two reported an increasing trend. Increasing trend (improvement) was significant for participant one (tau = -0.6222, *P<.001* and required correction.

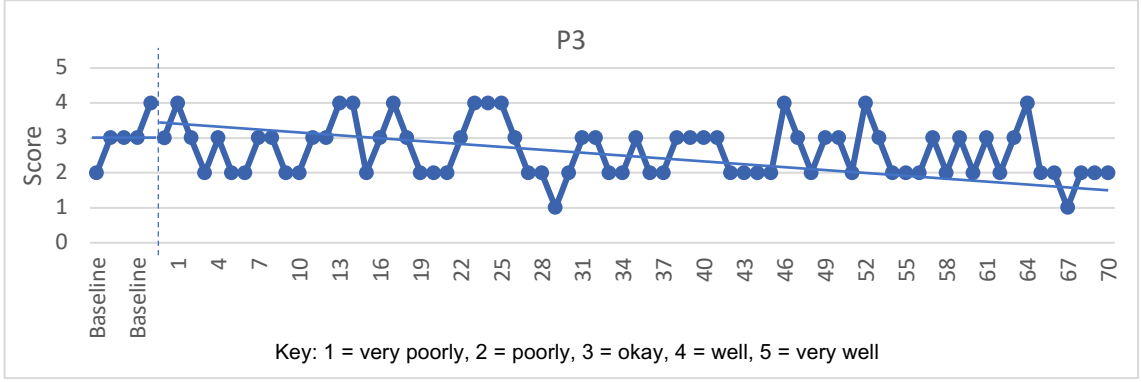
Intervention. Visual analysis and tau statistics indicate a significant improvement was observed for three participants (1: tau-U = 0.46, *p <0.05,* 90% CI 0.137-0.783; 4: tau-U = 0.742,

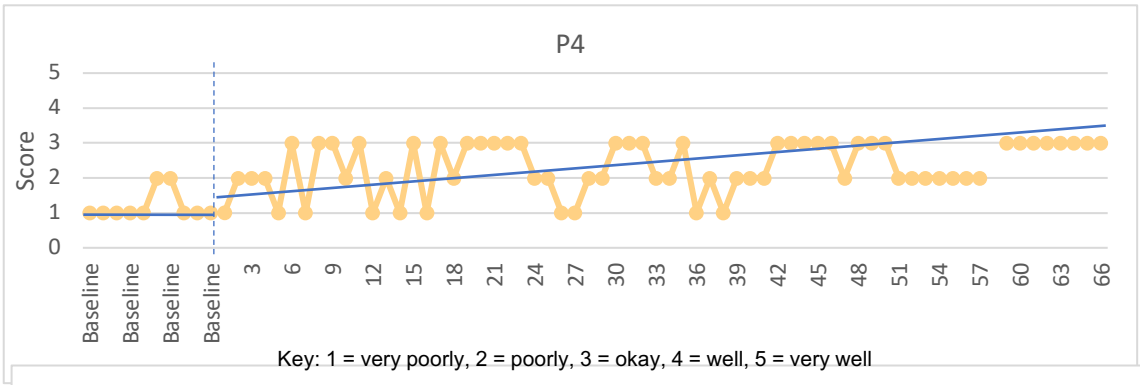
p<.001, 90% CI 0.417-1; 6: tau-U = 0.481, *p*<0.05, CI 90% 0.103-0.858). No change was observed for two participants (2: tau-U =0.31, *p*= 0.135, CI 90% = -0.031-0.651; 5: tau-U = 0.079, *p*=0.709, CI 90% = -0.269-0.427). For participant three, trend by visual analysis indicated a deterioration over intervention moving from a median answer of "okay" to "poorly", though tau-U statistic indicated this was not significant (tau-U = -0.3024, *p*=0.221, CI 90% = -0.709-0.104). Participants one and four indicated change was gradual over the intervention whilst change in level was reported from the beginning of the intervention by participant six. Overall change across participants was significant (tau = 0.327, *P<0.001*, 95% CI: 0.149-0.494).

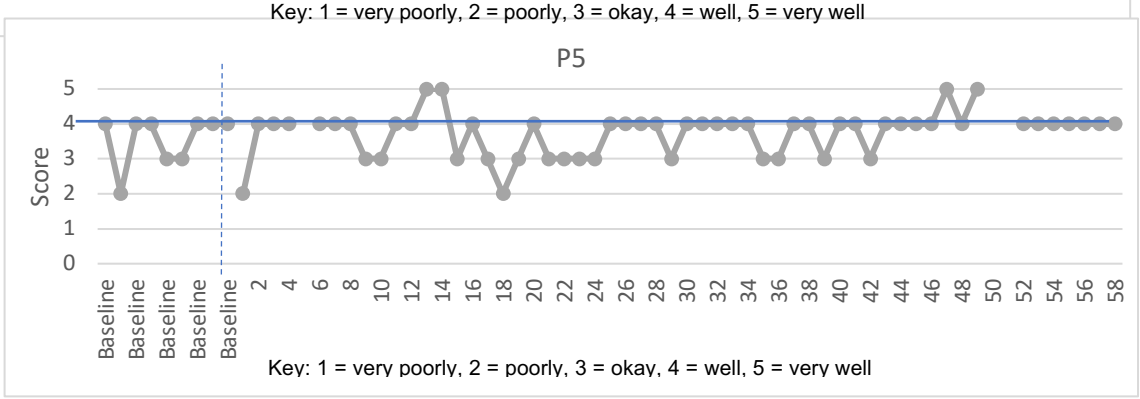
Figure two: Responses to daily question "*How well do you feel you are dealing with the physical consequences of your health condition today?"*



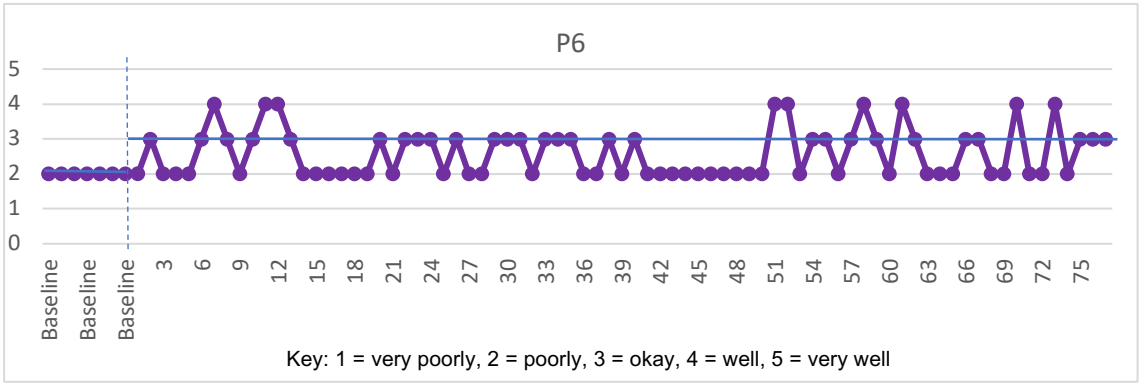








Key: 1 = very poorly, 2 = poorly, 3 = okay, 4 = well, 5 = very well



Question: *How able do you feel to talk to yourself with wisdom, strength, warmth and non-judgment today?*

Baseline. Decreasing trend was observed in two participants (1 & 6) during their baseline. Three participants reported stable baselines (2, 3 & 4) and one reported an increasing trend (5).

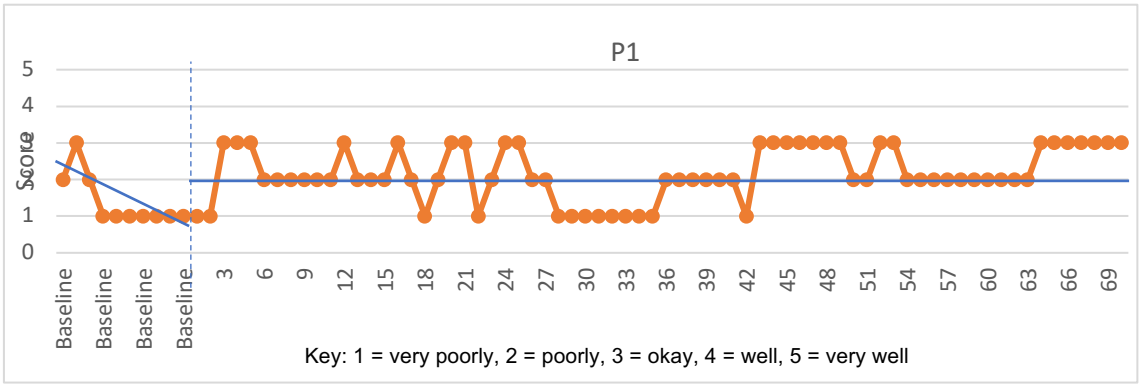
Intervention. Visual analysis and tau statistics indicate significant change over the intervention period for three participants (1: tau-U = 0.54, *p <0.001,* 90% CI 0.217-0.863; 2: tau-U = 0.6398, *p<.05,* 90% CI = 0.299-0.981; 4: tau-U = 0.5 , p<.05, 90% CI = 0.176<>0.824). Change in level

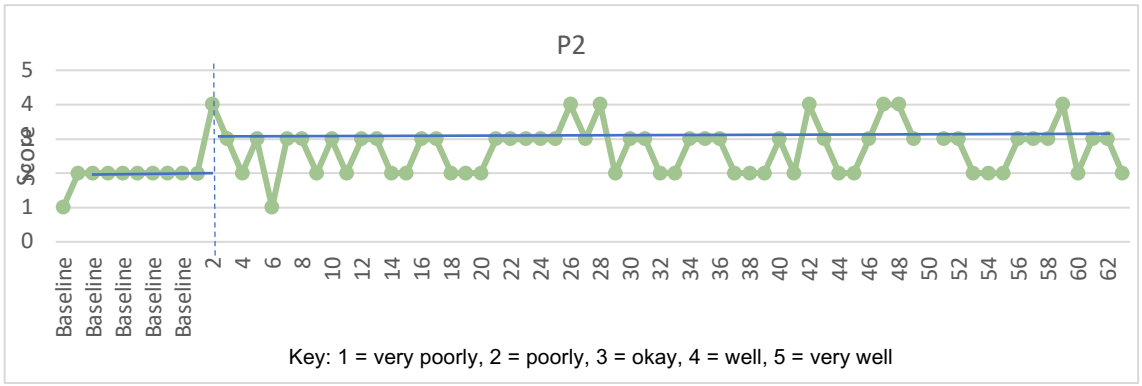
was immediate for participants one and two with no change in the first three weeks of the intervention for participant four before gradual increase in trend from week three.

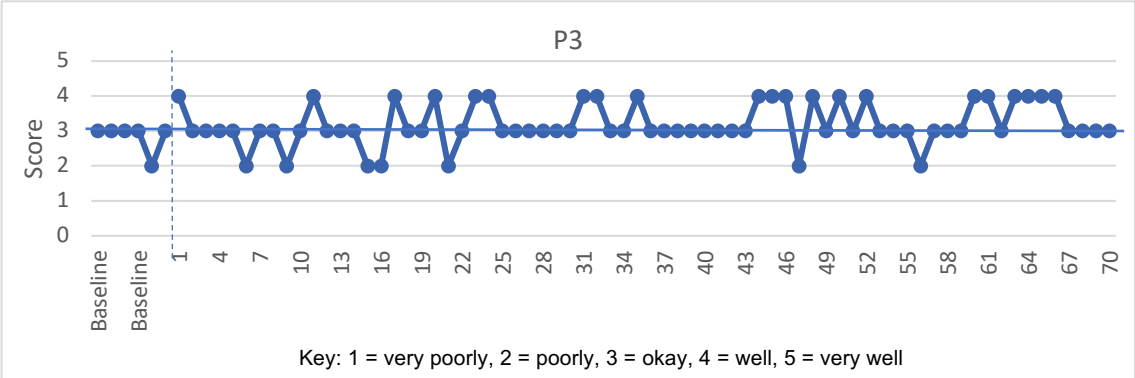
Change over time was not significant for three participants according tau-U statistic (3: tau-U = 0.3167, *p*=0.2, CI 90% = -0.090-0.723; 5: tau-U = 0.3214, *p*=0.124, CI 90% = -0.022-0.665; 6: tau-U = 0.193, *p*=0.4, CI 90% = -0.184-0.570).

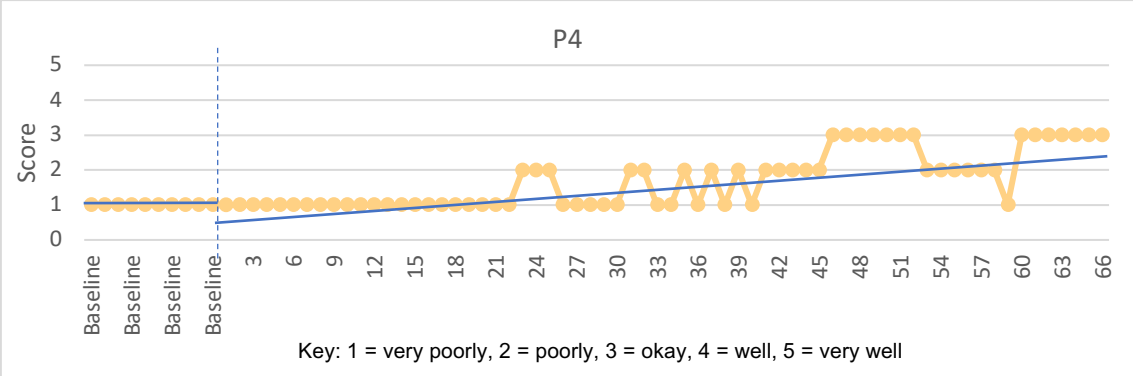
There was a discrepancy between visual analysis and tau statistics for participants five and six, where therapeutic trend and changes in level were observed by visual analysis but not supported by statistical analysis. Increasing stability was reported by both participants as the intervention progressed.

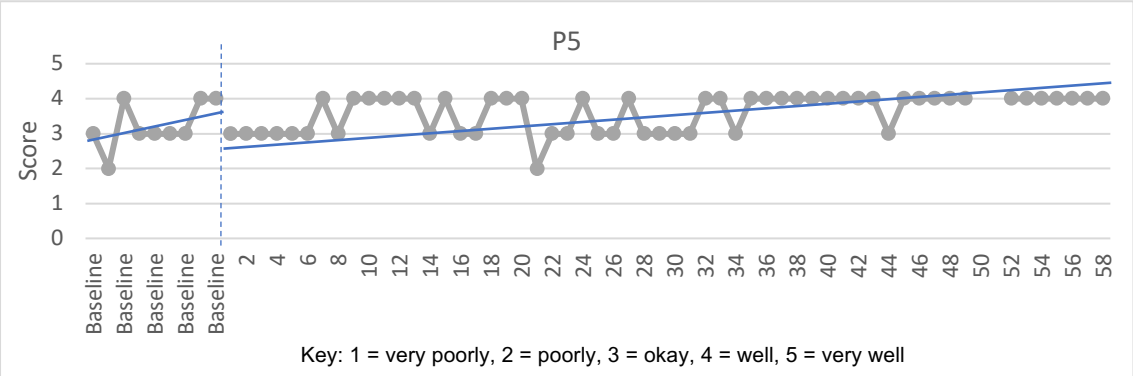
Figure Three: Responses to daily question "How able do you feel to talk to yourself with wisdom, strength, warmth and non-judgment today?"

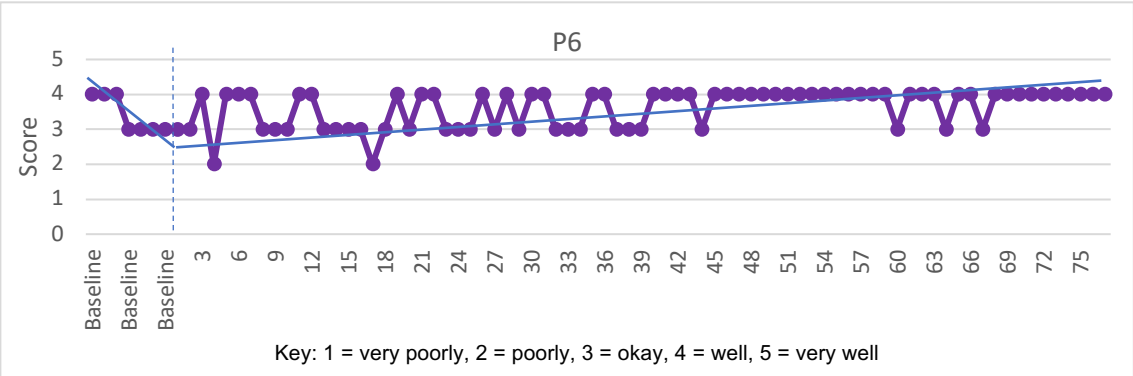












Weekly Battery

Pattern of change across individuals. Across the intervention period participants three, four and six reported a steady positive change in weekly battery scores. Participant two also reported gradual improvement over the first five weeks however this deteriorated following the break in the middle of the group. In line with participant five's self-report of finding the group challenging at the beginning, they reported an initial deterioration in scores before gradually increasing after week five. An overview of change by participant and measure can be seen in table 12.

Compassionate Engagement and Action Scale – Self Compassion. Four participants (see table three) reported reliable improvement across the full subscale. All participants reported reliable change in compassionate actions towards the self. Across participants trend in change indicated a gradual improvement over the intervention. Participant 6 reported a decrease between weeks 3-6 prior to sitting exams, these then improved to the previous range upon return in week nine.

Table Three: Pre and post scores of self-compassion

Participant	Baseline	End of group	RCI	CSC	Interpretation
1	55	56	T: 0.176		T: No change
	A: 13	A: 18	A: 4.197		A: Improved
2	49	69	T: 3.518	Total:	T: Recovered
	A: 17	A: 29	A: 10.07	≧56.465	A: Recovered
3	57	61	T: 0.704		T: No change
	A: 20	A: 26	A: 5.036	Action:	A: Recovered
4	28	48	T: 3.518	≧18.027	T: Improved
	A: 13	A: 24	A: 9.233		A: Recovered
5	51	74	T: 3.87		T: Recovered
	A:18	A:30	A: 10.07		A: Recovered
6	54	84	T: 5.277		T: Recovered
	A: 16	A: 31	A: 12.59		A: Recovered

^ T = total scale, A = action subscale

Compassionate Engagement and Action Scale – Giving compassion to others. One participant (6) reported reliable and clinically significant improvement across engagement and action in giving compassion to others. Three participants (2, 3 & 4) reported reduced compassionate action towards others. There was no consistent pattern or trend in these changes across the intervention. Two thirds of participants' baseline scores exceeded cut-scores for clinical significance

at baseline indicating they reported compassion to others at a similar level to the general population prior to the intervention (see table four).

Table Four: Pre and post scores of compassion to others

Participant	Baseline	End of group	RCI	CSC	Interpretation
1	75	77			
	E: 45	E: 49	E: 0.878		E: No change
	A: 30	A: 28	A: -1.71		A: No change
2	63	62			
	E:36	E: 38	E: 0.439		E: No change
	A:27	A: 24	A: -2.57	Engagement:	A: Deterioration
3	94	70		≧43.878	
	E: 60	E: 42	E: -3.95	Action:	E: Deterioration
	A: 34	A: 28	A: -5.14	≧30.04	A: Deterioration
4	93	85			
	E: 59	E: 54	E: -1.1		E: No change
	A: 34	A: 31	A: -2.57		A: Deterioration
5	78	74			
	E: 46	E: 44	E: -0.44		E: No change
	A: 32	A: 30	A: -1.71		A: No change
6	65	85			
	E: 38	E: 52	E: 3.073		E: Recovered
	A: 27	A: 33	A: 5.137		A: Recovered

^E= engagement subscale, A = action subscale

Compassionate Engagement and Action Scale – Receiving compassion from others. One participant (2) reported positive change engaging in, and receiving compassion from others. Three (1, 2 & 6) reported positive change in increased acceptance of actions of compassion from others. One participant (4) reported a clinically significant reduction in accepting actions of compassion from others. Reported scores fluctuated for all participants across the intervention, with no consistent pattern. Two thirds of participants (see table five) reported baseline scores within the normative range for the general population.

Table Five: Pre and post scores – CEAS receiving compassion subscale

Participant	Baseline	End of group	RCI	CSC	Interpretation
1	54 E: 33 A: 21	62 E: 35 A: 27	E: 0.553 A: 3.858	Engagement: ≧36.883 Action: ≧26.877	E: No change A: Improvement
2	78 E:44 A:34	63 E:37 A:26	E: -1.94 A: - 5.14		E: No change A: Deterioration
3	86 E:52 A:34	76 E:47 A:29	E: -1.38 A: - 3.21		E: No change A: Deterioration
4	59 E: 28 A:31	43 E:24 A:19	E: - 1.11 A: - 7.72		E: No change A: Deterioration
5	75 E:46 A:29	76 E:46 A:30	E: 0.00 A: 0.643		E: No change A: No change
6	70 E:43 A:27	78 E:47 A:31	E: 1.107 A: 2.572		E: No change A: Improvement

^E= engagement subscale, A = action subscale

Self-efficacy for managing chronic disease scale. Improved self-efficacy in managing conditions was reported by two participants and deterioration by one (see table six). Participants from the first cohort reported lower self-efficacy at baseline. Patterns of change over the intervention varied; all participants reported a decrease in perceived self-efficacy over the first four weeks. This began to increase from week six and continued to improve beyond baseline for participants two, three and four. Participant six missed weeks 6-8 of the group and scores which had been stable significantly deteriorated following this.

Table Six: Pre and post intervention scores - Self-Efficacy

Participant	Baseline	End of group	RCI	CSC	Interpretation
1	2.17	1	-1.13	≧9.47	Unchanged
2	2.83	5.33	2.425		Improved
3	2	3.17	1.135		Improved
4	8.33	7.67	-0.64		Unchanged
5	6.83	7.67	0.815		Unchanged

6	5.5	4.17	-1.29	Deteriorated

Warwick Edinburgh Mental Wellbeing Scale. Four participants reported improvement in wellbeing which demonstrated minimally important change (Tennant et al., 2007). In relation to the interpretation shown in table seven, those 'unchanged' refer to not increasing beyond the RCI. Two participants (3 & 4) reported wellbeing scores within the "average" range for the general population at the end of the intervention. Four participants scores remained in the "low" wellbeing category. Participant two's range of scores was significantly higher during the intervention than reported at baseline. This may represent a clear level change with onset of intervention, or baseline may not be representative of wellbeing prior to the group. Where change was reported, scores had been stable through to around week seven, with increases for four participants from week seven.

Table Seven: Pre- and post-intervention scores on the WEMWBS

Participant	Baseline	End of group	Minimally Important Change	RCI	CSC	Interpretation
1	21	31	Y	3.089	≧42.57	Improved
2	30	35	Y	1.545		Unchanged
3	43	44	N	0.309		Unchanged*
4	40	44	Y	1.236		Unchanged*
5	33	39	Y	1.85		Unchanged
6	41	41	N	0		Unchanged

* End of group score in 'average' range for general population however, RCI not exceeded

Illness Cognitions Scale – Acceptance. Two participants reported meaningful change in acceptance (table eight). Four participants reported no change. Visual analysis of weekly scores indicates change was gradual over the ten weeks. Visual analysis also demonstrated an increasing trend for participant five, whose scores at week one were lower than baseline, increasing steadily from this point.

Table Eight: Pre and post intervention scores - ICQ Acceptance subscale

Participant	Baseline	End of group	RCI	CSC	Interpretation
1	9	6	-2.12	≧18.51	No change
2	13	14	0.706		No change
3	6	6	0		No change
4	14	21	4.94		Recovered
5	16	18	1.411		No change
6	13	16	2.117		Improved

Illness Cognitions Scale – Helplessness. One participant reported reduced helplessness (table nine). No other meaningful change was reported by statistical analysis. Visual analysis of change over weekly scores indicated a therapeutic trend with helplessness gradually reducing for four participants (1, 3, 5 & 6).

Table Nine: Pre and post intervention scores – ICQ helplessness subscale

Participant	Baseline	End of group	RCI	CCS	Interpretation
1	12	13	- 0.42	≦6.55	No change
2	19	15	1.7		No change
3	24	24	0		No change
4	19	12	2.97		Improved
5	11	14	-1.27		No change
6	12	11	0.42		No change

Illness Cognitions Scale – Perceived Benefits. One participant (5) demonstrated significant improvement and four participants (1, 2, 3 & 4) scores of perceived benefits remained stable (table ten). A deterioration was observed for one (6) participant using visual analysis of weekly scores.

Table Ten: Pre and post intervention scores – ICQ perceived benefits subscale

Participant	Baseline	End of group	RCI	MCS	Interpretation
1	6	6	0	≧26.65	No change
2	21	17	-1.07		No change
3	9	7	-.54		No change
4	22	24	.535		No change
5	8	15	1.87		Improved
6	17	18	.268		No change

Work and Social Adjustment Scale. Social functioning reliably improved for participants two and four (table eleven). A therapeutic trend was observed in participant six which did not reach

statistical significance. A deterioration in social functioning was observed in participant one. This was gradual over the course of the group. Patterns of change were variable, with gradual improvement in 2, 4 and 6, and initial deterioration then stabilisation in participant 5. Three participants (3, 4 & 6) scores remained in the moderately-severe psychopathology range (>20). No participants end of group scores fell within the subclinical category (<10).

Table Eleven: Pre and post intervention scores – work and social adjustment

Participant	Baseline	End of group	RCI	CSC	Interpretation
1	19	26	-1.43	≦7.53	Unchanged
2	26	19	1.426		Improved
3	32	34	-0.41		Unchanged
4	34	22	2.445		Improved
5	13	12	0.204		Unchanged
6	16	13	0.611		Unchanged

Table Twelve: Clinically significant change descriptors across participants and measures

	Measure	Participants					
		1	**2**	**3**	**4**	**5**	**6**
Daily	Emotional consequences	+	-	-	+	-	+
	Physical consequences	+	-	x	+	-	+
	Compassion	+	+	-	+	+	+
Weekly	Self-compassion	+	++	++	++	++	++
	Giving compassion	-	x	x	x	-	++
	Receiving compassion	+	x	x	x	-	+
	WEMWBS*	+	+	-	+	+	-
	Self-efficacy	-	+	+	-	-	x
	WASA	-	-	+	-	+	-
	Helplessness	-	-	-	+	-	-
	Perceived benefit	-	-	-	-	+	-
	Acceptance	-	-	-	++	-	+

^Key: ++ recovered, + improved, - no change, x deteriorated

*WEMWBS results using minimally important change criteria

Discussion

With a growing evidence base suggesting that Compassion Focussed interventions are beneficial in improving the psychological wellbeing of individuals living with long term physical health conditions (LTCs), this study aimed to evaluate if a group based CFT intervention was effective when delivered through a group with multiple and various LTCs. In particular to identify in what areas change was affected, the process and trajectory of this change, and whether this was similar across individuals with living with different LTCs.

This study indicates the Rebalance group, delivered with varied staff and in different group cohorts, fosters a gradual increase in self-compassion over time. The improvements seen within individuals on measures deemed to reflect psychological adjustment to illness (self-efficacy, psychological wellbeing, illness cognitions, social functioning) were variable, with the most improvement seen in psychological wellbeing. The pattern predominately reported across measures and individuals was one of change over time, with gradual improvement over the course of the intervention.

Increased self-compassion has consistently been linked to reduced psychological distress and greater emotional resilience and stability (MacBeth & Gumley, 2012a; Neff, 2011). It has also been associated with improved health behaviours and adjustment to illness (Biber & Ellis, 2019; Brion et al., 2014). This study adds preliminary evidence to the field in demonstrating a structured CFT group intervention increases self-compassion for individuals with multiple and various chronic health conditions.

Traditionally, increased compassion in all directions is deemed to be positive. With regards to giving compassion to others two thirds of participants in this study were within the range of normative data for the general population at baseline. The deterioration of these scores during intervention requires further investigation. Theoretical hypothesis that could be explored include

whether individuals who are selected for the intervention demonstrate high levels of trait empathy and prioritise attending to the needs of others before themselves or; whether participants' understanding of compassion changed over the intervention and this is reflected in the reduced scores. Similarly, reported reduction in receiving compassion from others may be a consequence of a deeper understanding of the multiple facets of compassion which allows for reconsideration of others' and own actions. Normative baseline scores could also be hypothesised to indicate that compassion to and from others, has less impact upon psychological distress or adjustment to illness in comparison to self-compassion. Each of these hypotheses would warrant further investigation in order to clarify the role of compassionate flows in interventions targeting adjustment to illness.

With regards to adjustment, patterns of gradual change fit with the concept of adjustment as a process over time. No clear pattern was observed with regards to which psychological constructs changed consistently over the intervention. This highlights the multiple domains which encapsulate adjustment to illness. Despite all participants being referred to the service with a view to facilitating adjustment, variation at baseline also speaks to no one clear factor being predictive of distress.

One domain in which little change was observed was illness cognitions. In particular, change in perceived benefits or helplessness was not observed. The way in which individuals think about illness has long been associated with psychological distress and poor adjustment (Moss-Morris, 2013). If and how compassion impacts this relationship is not clear. In this intervention individuals anecdotally described living a more valued life i.e. improved meaningful functioning, despite illness cognitions not changing. Whether it is possible to hold predominately negative views of illness and demonstrate self-compassion requires further exploration.

Clinical Implications

A group-based programme of CFT for individuals with various and multiple LTCs feasible and efficacious in improving reported self-compassion. From a service perspective this format is less

restrictive than traditional illness-specific interventions. It prevents people with multimorbid health conditions needing to access multiple services or choose one to prioritise. The trend of change where improvement was reported, i.e. gradual over the full intervention, indicates the length of programme to be appropriate. Scores had not stabilised at week ten and therefore, it would not be indicated to shorten the group at this time. Consistent change in self-compassion adds to evidence that a generalist CFT intervention i.e. not tailored to an illness group, can be effective across LTCs.

From a compassion perspective, including individuals with varied health conditions provides a demonstration of the commonality of human suffering, whilst also creating an environment to model giving and receiving compassion from others. Qualitatively, participants and facilitators describe the first weeks of Rebalance to be emotionally and interpersonally challenging. Those invited to attend have been referred due to high levels of self-criticism and low self-compassion which is assessed as contributing to distress. Therefore, beginning to discuss and foster engagement in self-compassion can be challenging and often uncomfortable. Continuing to attend despite this is in itself an act of self-compassion.

Throughout this study many factors relating to the planning and facilitating of a therapeutic group were raised. Group dynamics were reported to have been different between the two groups with the second demonstrating more self-reflection and compassion within the room. The need for careful planning for a mix of interpersonal styles was raised. This is in line with a significant body of research on effective therapeutic groups. For a thorough guideline on planning and running group interventions Bernard et al. (2008) is recommended.

Theoretical Implications

Changes in self-compassion add to the body of evidence indicating compassion is a transdiagnostic factor, relevant across population groups. Interventions in LTC populations have demonstrated efficacy in improving psychological wellbeing and loneliness (Austin et al., 2020). However, changes to self-compassion without consistent change to measures reflecting adjustment

suggests other factors may be involved in this relationship. It may be that Rebalance is facilitating an emotional change in approach to LTCs, with individuals able to generate a more compassionate, less critical voice towards themselves. However, additional intervention targets may be required to produce improved adjustment. For example, more concrete behavioural strategies e.g. pacing or value driven activity may be beneficial. Alternatively, it could be that changes in adjustment continue to develop after the intervention and with longer follow-up improvement would have be reported.

Future research would benefit from further exploring the factors that may mediate or moderate the relationship between compassion and adjustment. In particular, psychological flexibility may be of interest as concepts such as cognitive fusion have been demonstrated to predict and account for illness-related shame and psychological distress in LTC populations (Maddison et al, 2020). Further SCED could also apply interventions in a modularised manner for example, baseline = 'period A', CFT = 'period B', then adding another strategy e.g. behavioural activation or monitoring only, in 'period C' to allow a deeper understanding of the process of change. With regards to measurement, monitoring the practice of compassion and mindfulness exercises between sessions would be of interest, with increased practice having recently been shown to predict improvement on outcome measures (Lloyd et al., 2018). Such a tangible, quantifiable measure would lend itself to SCED research. Feasibility trials could now also be run, randomising participants to the group CFT programme or treatment as usual. The key outcome measures of such trials would be self-compassion, and those that are consistently linked to psychological adjustment to illness e.g. psychological distress; self-management behaviours; adaptive coping styles (Sirois et al., 2016).

Limitations

This study looked at the effect of the Rebalance intervention across measures of compassion and adjustment. Validity is gained through replication and multiple baselines. However, it does not explore the wider context of each individuals' circumstances. For example, one participant

experienced an exacerbation of their illness during the group and changes in weekly scores reflected this. A qualitative exploration of this was not recorded however, may have helped to further understand and validate the pattern of change.

The reality of conducting the study in clinical practice was demonstrated through individuals missing weeks of the group. It could be argued that this gives a true reflection of what can be achieved in such settings where individuals have fluctuating health conditions, work and family commitments and public holidays affect service provision. Further, there is a self-selection bias in the sample reported; which is comprised of individuals who were able to seek help for a LTC, willing to attend a psychology service, a group intervention and participate in a research project. The ability to generalise results to all people with LTCs is therefore, not well established.

Only one set of weekly measures was taken at baseline and therefore, stability of baseline cannot be presumed on the longer standardised measures. Whilst most daily questions showed stability it is not possible to confer this stability to the weekly battery. Therefore, visual analysis and associated statistics would have been inappropriate. This decision was made based upon the characteristics of the population, in which a longer baseline collection period would not have been acceptable.

With regards to measurement, the three daily questions were developed collaboratively with a previous group. Whilst these were felt to be internally valid to the Rebalance intervention, it is acknowledged they are not generalisable or externally valid measures of adjustment or compassion.

Finally, clinical significance cut-offs were calculated to provide an indication of change over weekly measures. Some difficulty arose in this as calculations without normative data allowed cut-scores at the extreme end of scales e.g. SE at 9.47/ 10; ICQ perceived benefits exceeded the scale range with a cut score of 26.65/24. These cut scores raise questions about the level of distress reported at baseline. Indeed, where comparative data was available, on some measures the baseline results were close to general population normative data and so “recovery” would not be expected.

Further, on the WEMWBS, there was a discrepancy between CSC cut-scores and minimally important change levels in the reported literature.

Conclusion

This study demonstrated consistent significant increases in self-compassion over a ten-session group CFT intervention for individuals with various and/or multiple physical health conditions. The pattern of change across individuals indicates change to be gradual. Constructs linked to psychological adjustment changed variably across participants. Further research is required in order to determine factors that may be involved in the relationship between compassion and psychological adjustment to illness. A preliminary evaluation of the Rebalance CFT group programme has demonstrated replicable results across health conditions, group cohorts and group facilitators. This adds to the growing body of evidence indicating CFT based interventions to be clinically meaningful for populations living with physical health conditions.

References

Agostinis, A. (2007). The Development of a Microsoft Excel File for Psychologists in Clinical Training and Clinical Psychologists : The ‘ Leeds Reliable Change Index. *Change*.

Austin, J., Drossaert, C. H. C., Schroevers, M. J., Sanderman, R., Kirby, J. N., & Bohlmeijer, E. T. (2020). Compassion-based interventions for people with long-term physical conditions: a mixed methods systematic review. *Psychology & Health*, 1–27. https://doi.org/10.1080/08870446.2019.1699090

Baer, D. M., Wolf, M. M., & Risley, T. R. (1987). Some still-current dimensions of applied behavior analysis. Journal of Applied Behavior Analysis, 20(4), 313-327. https://doi.org/10.1901/jaba.1987.20-313

Barnett, K., Mercer, S. W., Norbury, M., Watt, G., Wyke, S., & Guthrie, B. (2012). Epidemiology of multimorbidity and implications for health care, research, and medical education: A cross-sectional study. *The Lancet*, *380*(9836), 37–43. https://doi.org/10.1016/S0140-6736(12)60240-2

Bernard, H., Burlingame, G., Flores, P., Greene, L., Joyce, A., Kobos, J. C., … Feirman, D. (2008). Clinical Practice Guidelines for Group Psychotherapy. *International Journal of Group Psychotherapy*, *58*(4).

Biber, D. D., & Ellis, R. (2019, December 1). The effect of self-compassion on the self-regulation of health behaviors: A systematic review. *Journal of Health Psychology*. SAGE Publications Ltd. https://doi.org/10.1177/1359105317713361

Brassington, L., Ferreira, N. B., Yates, S., Fearn, J., Lanza, P., Kemp, K., & Gillanders, D. (2016). Better living with illness: A transdiagnostic acceptance and commitment therapy group intervention for chronic physical illness. *Journal of Contextual Behavioral Science*. https://doi.org/10.1016/j.jcbs.2016.09.001

Brion, J., Leary, M., & Drabkin, A. (2014). Self-compassion and reactions to serious illness: the case of HIV., 218–229. https://doi.org/10.1177/1359105312467391

Brossart, D. F., Laird, V. C., & Armstrong, T. W. (2018). Interpreting Kendall's Tau and Tau-U for single-case experimental designs. *Cogent Psychology*, *5*(1), 1–26. https://doi.org/10.1080/23311908.2018.1518687

Campos, R. C., Besser, A., Ferreira, R., & Blatt, S. J. (2012). Self-criticism, neediness, and distress among women undergoing treatment for breast cancer: A preliminary test of the moderating role of adjustment to illness. *International Journal of Stress Management*, *19*(2), 151–174. https://doi.org/10.1037/a0027996

Chida, Y., Hamer, M., & Steptoe, A. (2008). A Bidirectional Relationship Between Psychosocial Factors and Atopic Disorders: A Systematic Review and Meta-Analysis. *Psychosomatic Medicine*, *70*(1), 102–116. https://doi.org/10.1097/PSY.0b013e31815c1b71

Clegg, S., Sirois, F., & Reuber, M. (2019). Self-compassion and adjustment in epilepsy and psychogenic nonepileptic seizures. *Epilepsy and Behavior*, *100*(Pt A), 106490. https://doi.org/10.1016/j.yebeh.2019.106490

de Ridder, D., Geenen, R., Kuijer, R., & van Middendorp, H. (2008). Psychological adjustment to chronic disease. *The Lancet*, *372*(9634), 246–255. https://doi.org/10.1016/S0140-6736(08)61078-8

Department of Health. (2012). *Long Term Conditions Compendium of Information Third Edition*.

Evers, A. W., Kraaimaat, F. W., van Lankveld, W., Jongen, P. J., Jacobs, J. W., & Bijlsma, J. W. (2001). Beyond unfavorable thinking: the illness cognition questionnaire for chronic diseases. *Journal of Consulting and Clinical Psychology*, *69*(6), 1026–1036.

Gilbert, P., Catarino, F., Duarte, C., Matos, M., Kolts, R., Stubbs, J., … Basran, J. (2017). The development of compassionate engagement and action scales for self and others. *Journal of Compassionate Health Care*, *4*(1), 4. https://doi.org/10.1186/s40639-017-0033-3

Gilbert, P., & Procter, S. (2006). Compassionate mind training for people with high shame and self-criticism: overview and pilot study of a group therapy approach. *Clinical Psychology & Psychotherapy*, *13*(6), 353–379. https://doi.org/10.1002/cpp.507

Jacobson, N. S., & Truax, P. (1991). Clinical Significance: A Statistical Approach to Defining Meaningful Change in Psychotherapy Research. *Journal of Consulting and Clinical Psychology*, *59*(1), 12–19. https://doi.org/10.1037/0022-006X.59.1.12

Kazdin, A. E. (2016). *Methodological issues and strategies in clinical research*. American Psychological Association.

Kazdin, A. E. (2019). Single-case experimental designs. Evaluating interventions in research and clinical practice. Behaviour research and therapy, 117, 3-17. https://doi.org/10.1016/j.brat.2018.11.015

Lastrucci, V., Lorini, C., Caini, S., Florence Health Literacy Research Group, & Bonaccorsi, G. (2019). Health literacy as a mediator of the relationship between socioeconomic status and health: A cross-sectional study in a population-based sample in Florence. *PloS One*, *14*(12), e0227007. https://doi.org/10.1371/journal.pone.0227007

Lorig, K. R., Ritter, P., Stewart, A. L., Sobel, D. S., Brown, B. W., Bandura, A., … Holman, H. R. (2001). Chronic disease self-management program: 2-year health status and health care utilization outcomes. *Medical Care*, *39*(11), 1217–1223.

MacBeth, A., & Gumley, A. (2012). Exploring compassion: A meta-analysis of the association between self-compassion and psychopathology. *Clinical Psychology Review*. https://doi.org/10.1016/j.cpr.2012.06.003

Maddison, A., Halliday, G., & Gillanders, D. (2020). Illness-related shame and associated outcomes: A systematic review. *Journal of Behavioral Medicine*, *in prep*.

Morley, S., & Dowzer, C. N. (2014). *The Leeds Reliable Change Indicator* .

Moss-Morris, R. (2013). Adjusting to chronic illness: Time for a unified theory. *British Journal of Health Psychology*, *18*(4), 681–686. https://doi.org/10.1111/bjhp.12072

Mundt, J. C., Marks, I. M., Shear, M. K., & Greist, J. H. (2002). The Work and Social Adjustment Scale: a simple measure of impairment in functioning. *The British Journal of Psychiatry : The Journal of Mental Science*, *180*, 461–464.

National Institute for Health and Care Excellence. (2017). Overview | Multimorbidity | Quality standards | NICE. Retrieved April 6, 2020, from https://www.nice.org.uk/guidance/qs153

Naylor, C., Das, P., Ross, S., Honeyman, M., Thompson, J., & Gilburt, H. (2016). Bringing together physical and mental health A new frontier for integrated care.

Naylor, C., Parsonage, M., Mcdaid, D., Knapp, M., Fossey, M., & Galea, A. (2012). Long-term conditions and mental health The cost of co-morbidities.

Neff, K. D. (2011). Self-Compassion, Self-Esteem, and Well-Being. *Social and Personality Psychology Compass*, *5*, 1–12. https://doi.org/10.1111/j.1751-9004.2010.00330.x

Ohrnberger, J., Fichera, E., & Sutton, M. (2017). The relationship between physical and mental health: A mediation analysis. *Social Science and Medicine*, *195*, 42–49. https://doi.org/10.1016/j.socscimed.2017.11.008

Parker, R. I., Vannest, K. J., & Davis, J. L. (2011). Effect size in single-case research: a review of nine nonoverlap techniques. *Behavior Modification*, *35*(4), 303–322. https://doi.org/10.1177/0145445511399147

Parker, R. I., Vannest, K. J., Davis, J. L., & Sauber, S. B. (2011). Combining Nonoverlap and Trend for Single-Case Research: Tau-U. *Behavior Therapy*, *42*(2), 284–299. https://doi.org/10.1016/j.beth.2010.08.006

Renn, B. N., Feliciano, L., & Segal, D. L. (2011, December 1). The bidirectional relationship of depression and diabetes: A systematic review. *Clinical Psychology Review*. Pergamon. https://doi.org/10.1016/j.cpr.2011.08.001

Ritter, P. L., & Lorig, K. (2014). The English and Spanish Self-Efficacy to Manage Chronic Disease Scale measures were validated using multiple studies. *Journal of Clinical Epidemiology*, *67*(11), 1265–1273. https://doi.org/10.1016/j.jclinepi.2014.06.009

Royal College of Psychiatrists. (2013). *Liaison psychiatry for every acute hospital* . London.

Rudich, Z., Lerman, S. F., Gurevich, B., Weksler, N., & Shahar, G. (2008). Patients' Self-Criticism Is a Stronger Predictor of Physician's Evaluation of Prognosis Than Pain Diagnosis or Severity in Chronic Pain Patients. *Journal of Pain*, *9*(3), 210–216. https://doi.org/10.1016/j.jpain.2007.10.013

Scottish Government. (2015a). Long Term Conditions. Retrieved June 5, 2018, from http://www.gov.scot/Topics/Health/Services/Long-Term-Conditions

Scottish Government. (2015b). *The Matrix (2015) A Guide to Delivering Evidence-Based Psychological Therapies in Scotland*.

Sharpe, L., & Curran, L. (2006). Understanding the process of adjustment to illness. *Social Science & Medicine*, *62*, 1153–1166. https://doi.org/10.1016/j.socscimed.2005.07.010

Sirois, F. M., Molnar, D. S., & Hirsch, J. K. (2015). Self-Compassion, Stress, and Coping in the Context of Chronic Illness. *Self and Identity*, *14*(3), 334–347. https://doi.org/10.1080/15298868.2014.996249

Sirois, F. M., Rowse, G., & Review, D. C. (2016). *The Role of Self-Compassion in Chronic Illness Care*. *www.jcomjournal.com* (Vol. 23).

Tennant, R., Hiller, L., Fishwick, R., Platt, S., Joseph, S., Weich, S., … Stewart-Brown, S. (2007). Health and Quality of Life Outcomes The Warwick-Edinburgh Mental Well-being Scale (WEMWBS): development and UK validation. https://doi.org/10.1186/1477-7525-5-63

Wren, A. A., Somers, T. J., Wright, M. A., Goetz, M. C., Leary, M. R., Fras, A. M., … Keefe, F. J. (2012). Self-Compassion in Patients With Persistent Musculoskeletal Pain: Relationship of Self-Compassion to Adjustment to Persistent Pain. *Journal of Pain and Symptom Management*, *43*, 759–770. https://doi.org/10.1016/j.jpainsymman.2011.04.014

Yalom, I. D., & Leszcz, M. (2005). *The theory and practice of group psychotherapy*. Basic Books.

Thesis portfolio references

A-Tjak, J., Davis, M., Morina, N., Powers, M., Smits J, & Emmelkamp, P. (2015). A Meta-Analysis of the Efficacy of Acceptance and Commitment Therapy for Clinically Relevant Mental and Physical Health Problems. *Psychotherapy and Psychosomatics*, *84*, 30–36. https://doi.org/10.1159/000365764

Agostinis, A. (2007). The Development of a Microsoft Excel File for Psychologists in Clinical Training and Clinical Psychologists : The ' Leeds Reliable Change Index. *Change*.

Andrews, B., Qian, M., & Valentine, J. D. (2002). Predicting depressive symptoms with a new measure of shame: The Experience of Shame Scale. *British Journal of Clinical Psychology*, *41*(1), 29–42. https://doi.org/10.1348/014466502163778

Ashworth, F., Clarke, A., Jones, L., Jennings, C., & Longworth, C. (2014). An exploration of compassion focused therapy following acquired brain injury. *Psychology and Psychotherapy: Theory, Research and Practice*. https://doi.org/10.1111/papt.12037

Austin, J., Drossaert, C. H. C., Schroevers, M. J., Sanderman, R., Kirby, J. N., & Bohlmeijer, E. T. (2020). Compassion-based interventions for people with long-term physical conditions: a mixed methods systematic review. *Psychology & Health*, 1–27. https://doi.org/10.1080/08870446.2019.1699090

Baer, D. M., Wolf, M. M., & Risley, T. R. (1987). Some still-current dimensions of applied behavior analysis. Journal of Applied Behavior Analysis, 20(4), 313-327. https://doi.org/10.1901/jaba.1987.20-313

Barnett, K., Mercer, S. W., Norbury, M., Watt, G., Wyke, S., & Guthrie, B. (2012). Epidemiology of multimorbidity and implications for health care, research, and medical education: A cross-sectional study. *The Lancet*, *380*(9836), 37–43. https://doi.org/10.1016/S0140-6736(12)60240-2

Baumeister, R. F., & Leary, M. R. (1995). The Need to Belong: Desire for Interpersonal Attachments as a Fundamental Human Motivation. *Psychological Bulletin*, *117*(3), 497–529. https://doi.org/10.1037/0033-2909.117.3.497

Baumeister, R. F., Stillwell, A. M., & Heatherton, T. F. (1994). Guilt: An interpersonal approach. *Psychological Bulletin*, *115*(2), 243–267. https://doi.org/10.1037/0033-2909.115.2.243

Bernard, H., Burlingame, G., Flores, P., Greene, L., Joyce, A., Kobos, J. C., … Feirman, D. (2008). Clinical Practice Guidelines for Group Psychotherapy. *International Journal of Group Psychotherapy*, *58*(4).

Biber, D. D., & Ellis, R. (2019, December 1). The effect of self-compassion on the self-regulation of health behaviors: A systematic review. *Journal of Health Psychology*. SAGE Publications Ltd. https://doi.org/10.1177/1359105317713361

Birchwood, M., Jackson, C., Brunet, K., Holden, J., & Barton, K. (2012). Personal beliefs about illness questionnaire-revised (PBIQ-R): Reliability and validation in a first episode sample. *British Journal of Clinical Psychology*, *51*(4), 448–458. https://doi.org/10.1111/j.2044-8260.2012.02040.x

Boquiren, V. M., Esplen, M. J., Wong, J., Toner, B., & Warner, E. (2013). Exploring the influence of gender-role socialization and objectified body consciousness on body image disturbance in breast cancer survivors. *Psycho-Oncology*, *22*(10), n/a-n/a. https://doi.org/10.1002/pon.3271

Brassington, L., Ferreira, N. B., Yates, S., Fearn, J., Lanza, P., Kemp, K., & Gillanders, D. (2016). Better living with illness: A transdiagnostic acceptance and commitment therapy group intervention for chronic physical illness. *Journal of Contextual Behavioral Science*. https://doi.org/10.1016/j.jcbs.2016.09.001

Brion, J., Leary, M., & Drabkin, A. (2014). Self-compassion and reactions to serious illness:

the case of HIV., 218–229. https://doi.org/10.1177/1359105312467391

Brion, J. M., Leary, M. R., & Drabkin, A. S. (2014). Self-compassion and reactions to serious illness: The case of HIV. *Journal of Health Psychology*, *19*(2), 218–229. https://doi.org/10.1177/1359105312467391

British Psychological Society, T. (2008). Clinical Health Psychologists in the NHS.

Brossart, D. F., Laird, V. C., & Armstrong, T. W. (2018). Interpreting Kendall's Tau and Tau-U for single-case experimental designs. *Cogent Psychology*, *5*(1), 1–26. https://doi.org/10.1080/23311908.2018.1518687

Campos, R. C., Besser, A., Ferreira, R., & Blatt, S. J. (2012). Self-criticism, neediness, and distress among women undergoing treatment for breast cancer: A preliminary test of the moderating role of adjustment to illness. *International Journal of Stress Management*, *19*(2), 151–174. https://doi.org/10.1037/a0027996

Casati, J., Toner, B. B., De Rooy, E. C., Drossman, D. A., & Maunder, R. G. (2000). Concerns of patients with inflammatory bowel disease: A review of emerging themes. *Digestive Diseases and Sciences*. Springer. https://doi.org/10.1023/A:1005492806777

Castonguay, A. L., Wrosch, C., Pila, E., & Sabiston, C. M. (2017). Body-related shame and guilt predict physical activity in breast cancer survivors over time. *Oncology Nursing Forum*, *44*(4), 465–475. https://doi.org/10.1188/17.ONF.465-475

Chida, Y., Hamer, M., & Steptoe, A. (2008). A Bidirectional Relationship Between Psychosocial Factors and Atopic Disorders: A Systematic Review and Meta-Analysis. *Psychosomatic Medicine*, *70*(1), 102–116. https://doi.org/10.1097/PSY.0b013e31815c1b71

Clark, A. (2012). Working with guilt and shame . *Advances in Psychiatric Treatment*, *18*, 137–143. https://doi.org/10.1192/apt.bp.110.008326

Clegg, S., Sirois, F., & Reuber, M. (2019). Self-compassion and adjustment in epilepsy and psychogenic nonepileptic seizures. *Epilepsy and Behavior*, *100*(Pt A), 106490. https://doi.org/10.1016/j.yebeh.2019.106490

Conradt, M., Dierk, J.-M., Schlumberger, P., Rauh, E., Hebebrand, J., & Rief, W. (2007a). Development of the Weight- and Body-Related Shame and Guilt Scale (WEB–SG) in a Nonclinical Sample of Obese Individuals. *Journal of Personality Assessment*, *88*(3), 317–327. https://doi.org/10.1080/00223890701331856

Conradt, M., Dierk, J. M., Schlumberger, P., Rauh, E., Hebebrand, J., & Rief, W. (2007b). Development of the weight- and body-related shame and guilt scale (WEB-SG) in a nonclinical sample of obese individuals. *Journal of Personality Assessment*, *88*(3), 317–327. https://doi.org/10.1080/00223890701331856

Cuppage, J., Baird, K., Gibson, J., Booth, R., & Hevey, D. (2018). Compassion focused therapy: Exploring the effectiveness with a transdiagnostic group and potential processes of change. *British Journal of Clinical Psychology*, *57*(2), 240–254. https://doi.org/10.1111/bjc.12162

Davids, E. ., & Roman, N. . (2014). A systematic review of the relationship between parenting styles and children's physical activity. *African Journal for Physical Health Education*, *20*(2), 228–246.

de Ridder, D., Geenen, R., Kuijer, R., & van Middendorp, H. (2008). Psychological adjustment to chronic disease. *The Lancet*, *372*(9634), 246–255. https://doi.org/10.1016/S0140-6736(08)61078-8

Dekker, J., & de Groot, V. (2018). Psychological adjustment to chronic disease and rehabilitation – an exploration. *Disability and Rehabilitation*, *40*(1), 116–120. https://doi.org/10.1080/09638288.2016.1247469

Department of Health. (2012). *Long Term Conditions Compendium of Information Third*

Edition.

Dewsaran-van der Ven, C., van Broeckhuysen-Kloth, S., Thorsell, S., Scholten, R., De Gucht, V., & Geenen, R. (2018). Self-compassion in somatoform disorder. *Psychiatry Research*, *262*, 34–39. https://doi.org/10.1016/J.PSYCHRES.2017.12.013

Dolezal, L., & Lyons, B. (2017). Health-related shame: An affective determinant of health? *Medical Humanities*, *43*(4), 257–263. https://doi.org/10.1136/medhum-2017-011186

Dunkley, D. M., Schwartzman, D., Looper, K. J., Sigal, J. J., Pierre, A., & Kotowycz, M. A. (2012). Perfectionism dimensions and dependency in relation to personality vulnerability and psychosocial adjustment in patients with coronary artery disease. *Journal of Clinical Psychology in Medical Settings*, *19*(2), 211–223. https://doi.org/10.1007/s10880-011-9271-2

Evers, A. W., Kraaimaat, F. W., van Lankveld, W., Jongen, P. J., Jacobs, J. W., & Bijlsma, J. W. (2001). Beyond unfavorable thinking: the illness cognition questionnaire for chronic diseases. *Journal of Consulting and Clinical Psychology*, *69*(6), 1026–1036.

Fellows, J. L., Flower, L., Blakey, J., Kurukulaaratchy, R., Howard, R., & Mansur, A. (2015). Case series: The application of “third wave” cognitive behavioural therapies in difficult to treat asthma. *Journal of Asthma*. https://doi.org/10.3109/02770903.2014.1003155

Firth-Cozens, J., & Cornwell, J. (2009). *The point of care: Enabling compassionate care in acute hospital settings*. London.

Friis, A., Johnson, M., … R. C.-D., & 2016, undefined. (n.d.). Kindness matters: a randomized controlled trial of a mindful self-compassion intervention improves depression, distress, and HbA1c among patients with diabetes. *Am Diabetes Assoc*.

Gilbert, P., Durrant, R., & McEwan, K. (2006). Investigating relationships between perfectionism, forms and functions of self-criticism, and sensitivity to put-down. *Personality and Individual Differences*, *41*(7), 1299–1308.

https://doi.org/10.1016/j.paid.2006.05.004

Gilbert, P, & Andrews, B. (1998). *Shame: Interpersonal Behavior, Psychopathology, and Culture*. Oxford University Press.

Gilbert, P, & Miles, J. (2014). *Body Shame: Conceptualisation, Research and Treatment*. London: Routledge.

Gilbert, Paul. (1997). The evolution of social attractiveness and its role in shame, humiliation, guilt and therapy. *British Journal of Medical Psychology*, *70*(2), 113–147. https://doi.org/10.1111/j.2044-8341.1997.tb01893.x

Gilbert, Paul. (2000). The relationship of shame, social anxiety and depression: the role of the evaluation of social rank. *Clinical Psychology & Psychotherapy*, *7*(3), 174–189. https://doi.org/10.1002/1099-0879(200007)7:3<174::AID-CPP236>3.0.CO;2-U

Gilbert, Paul. (2014). The origins and nature of compassion focused therapy. *British Journal of Clinical Psychology*, *53*(1), 6–41. https://doi.org/10.1111/bjc.12043

Gilbert, Paul, Catarino, F., Duarte, C., Matos, M., Kolts, R., Stubbs, J., … Basran, J. (2017). The development of compassionate engagement and action scales for self and others. *Journal of Compassionate Health Care*, *4*(1), 4. https://doi.org/10.1186/s40639-017-0033-3

Gilbert, Paul, & Procter, S. (2006). Compassionate mind training for people with high shame and self-criticism: overview and pilot study of a group therapy approach. *Clinical Psychology & Psychotherapy*, *13*(6), 353–379. https://doi.org/10.1002/cpp.507

Harandi, T. F., Taghinasab, M. M., & Nayeri, T. D. (2017). The correlation of social support with mental health: A meta-analysis. *Electronic Physician*, *9*(9), 5212–5222. https://doi.org/10.19082/5212

Harder, D. W., Cutler, L., & Rockart, L. (1992). Assessment of Shame and Guilt and Their

Relationships to Psychopathology. *Journal of Personality Assessment*, *59*(3), 584–604. https://doi.org/10.1207/s15327752jpa5903_12

Hayes, S. C., Luoma, J. B., Bond, F. W., Masuda, A., & Lillis, J. (2006). Acceptance and Commitment Therapy: Model, processes and outcomes . *Behaviour Research and Therapy*, 44(1), 1–25.

Health Organization Regional Office for Europe, W. (2017). *Addressing comorbidity between mental disorders and major noncommunicable diseases*.

Hill, J., Holcombe, C., Clark, L., Boothby, M. R. K., Hincks, A., Fisher, J., … Salmon, P. (2011). Predictors of onset of depression and anxiety in the year after diagnosis of breast cancer. *Psychological Medicine*, *41*(7), 1429–1436. https://doi.org/10.1017/S0033291710001868

Hutchinson, P., & Dhairyawan, R. (2017). Shame, stigma, HIV: Philosophical reflections. *Medical Humanities*, *43*(4), 225–230. https://doi.org/10.1136/medhum-2016-011179

Hyphantis, T., Goulia, P., & Carvalho, A. F. (2013). Personality traits, defense mechanisms and hostility features associated with somatic symptom severity in both health and disease. *Journal of Psychosomatic Research*, *75*(4), 362–369. https://doi.org/10.1016/j.jpsychores.2013.08.014

Inwood, E., & Ferrari, M. (2018). Mechanisms of Change in the Relationship between Self-Compassion, Emotion Regulation, and Mental Health: A Systematic Review. *Applied Psychology: Health and Well-Being*. https://doi.org/10.1111/aphw.12127

Jacobson, N. S., & Truax, P. (1991). Clinical Significance: A Statistical Approach to Defining Meaningful Change in Psychotherapy Research. *Journal of Consulting and Clinical Psychology*, *59*(1), 12–19. https://doi.org/10.1037/0022-006X.59.1.12

James, K., Verplanken, B., & Rimes, K. A. (2015). Self-criticism as a mediator in the relationship between unhealthy perfectionism and distress. *Personality and Individual*

Differences, *79*, 123–128. https://doi.org/10.1016/j.paid.2015.01.030

Judge, L., Cleghorn, A., McEwan, K., & Gilbert, P. (2012). An Exploration of Group-Based Compassion Focused Therapy for a Heterogeneous Range of Clients Presenting to a Community Mental Health Team. *International Journal of Cognitive Therapy*, *5*, 420–429.

Kaufman, G. (1996). *The psychology of shame: Theory and treatment of shame-based syndromes*. Springer. https://doi.org/10.1016/s0191-8869(97)85593-6.

Kazdin, A. E. (2016). *Methodological issues and strategies in clinical research*. American Psychological Association.

Kazdin, A. E. (2019). Single-case experimental designs. Evaluating interventions in research and clinical practice. Behaviour research and therapy, 117, 3-17. https://doi.org/10.1016/j.brat.2018.11.015

Kim, S., Thibodeau, R., & Jorgensen, R. S. (2011). Shame, Guilt, and Depressive Symptoms: A Meta-Analytic Review. *Psychological Bulletin*, *137*(1), 68–96. https://doi.org/10.1037/a0021466

Kirby, J. N., Tellegen, C. L., & Steindl, S. R. (2017). A Meta-Analysis of Compassion-Based Interventions: Current State of Knowledge and Future Directions. *Behavior Therapy*, *48*, 778–792. https://doi.org/10.1016/j.beth.2017.06.003

Kolts, R. L. (2016). *CFT made simple : a clinician's guide to practicing compassion-focused therapy*.

Kupfer, J., Brosig, B., Niemeier, V., & Gieler, U. (2005). Zur Validität des Hautzufriedenheitsbogens (Hautzuf)–Validity of the Touch-Shame-Disgust-Questionnaire (TSD-Q). *Psychother Psychosom Med*. *55*(02), P_078

Lahousen, T., Kupfer, J., Gieler, U., Hofer, A., Linder, M. D., & Schut, C. (2016). Differences between psoriasis patients and skin-healthy controls concerning appraisal of touching,

shame and disgust. *Acta Dermato-Venereologica*, *96*, 78–82. https://doi.org/10.2340/00015555-2373

Lastrucci, V., Lorini, C., Caini, S., Florence Health Literacy Research Group, & Bonaccorsi, G. (2019). Health literacy as a mediator of the relationship between socioeconomic status and health: A cross-sectional study in a population-based sample in Florence. *PloS One*, *14*(12), e0227007. https://doi.org/10.1371/journal.pone.0227007

Lazare, A. (1987). Shame and Humiliation in the Medical Encounter, *Archives of internal medicine*, *147*(9), 1653-1658.

Leaviss, J., & Uttley, L. (2015). Psychotherapeutic benefits of compassion-focused therapy: an early systematic review. *Psychological Medicine*, *45*(05), 927–945. https://doi.org/10.1017/S0033291714002141

Lindsey, S. (2017). *Examining the Psychometric Properties of the Compassionate Engagement and Action Scales in the General Population*.

Lorig, K. R., Ritter, P., Stewart, A. L., Sobel, D. S., Brown, B. W., Bandura, A., … Holman, H. R. (2001). Chronic disease self-management program: 2-year health status and health care utilization outcomes. *Medical Care*, *39*(11), 1217–1223.

MacBeth, A., & Gumley, A. (2012a). Exploring compassion: A meta-analysis of the association between self-compassion and psychopathology. *Clinical Psychology Review*. https://doi.org/10.1016/j.cpr.2012.06.003

MacBeth, A., & Gumley, A. (2012b). Exploring compassion: A meta-analysis of the association between self-compassion and psychopathology. *Clinical Psychology Review*, *32*(6), 545–552. https://doi.org/10.1016/J.CPR.2012.06.003

Maddison, A., Halliday, G., & Gillanders, D. (2020). Illness-related shame and associated outcomes: A systematic review. *Journal of Behavioral Medicine*, *in prep*.

McFall, L., & Johnson, V. (2009). Shame: Concept Analysis. *Journal of Theory Construction & Testing*, *13*(2), 57–63.

Mckinley, N. M., & Hyde, J. S. (1996). The Objectified Body Consciousness Scale Development and Validation. *Psychology of Women Quarterly* (Vol. 20).

Mehr, K. E., & Adams, A. C. (2016). Self-Compassion as a Mediator of Maladaptive Perfectionism and Depressive Symptoms in College Students. *Journal of College Student Psychotherapy*, *30*(2), 132–145. https://doi.org/10.1080/87568225.2016.1140991

Minja, L., Cichowitz, C., Knettel, B. A., Mahande, M. J., Kisigo, G., Knippler, E. T., … Watt, M. H. (2019). Attitudes Toward Long-Term Use of Antiretroviral Therapy Among HIV-Infected Pregnant Women in Moshi, Tanzania: A Longitudinal Study. *AIDS and Behavior*, *23*(9), 2610–2617. https://doi.org/10.1007/s10461-019-02622-5

Moreira, H., & Canavarro, M. C. (2010). A longitudinal study about the body image and psychosocial adjustment of breast cancer patients during the course of the disease. *European Journal of Oncology Nursing*, *14*(4), 263–270. https://doi.org/10.1016/j.ejon.2010.04.001

Moreira, H., Silva, S., Marques, A., & Canavarro, M. C. (2010). The Portuguese version of the Body Image Scale (BIS) - psychometric properties in a sample of breast cancer patients. *European Journal of Oncology Nursing*, *14*(2), 111–118. https://doi.org/10.1016/j.ejon.2009.09.007

Morley, S., & Dowzer, C. N. (2014). *The Leeds Reliable Change Indicator* .

Moss-Morris, R. (2013). Adjusting to chronic illness: Time for a unified theory. *British Journal of Health Psychology*, *18*(4), 681–686. https://doi.org/10.1111/bjhp.12072

Mundt, J. C., Marks, I. M., Shear, M. K., & Greist, J. H. (2002). The Work and Social Adjustment Scale: a simple measure of impairment in functioning. *The British Journal of*

Psychiatry : The Journal of Mental Science, *180*, 461–464.

National Institute for Health and Care Excellence. (2017). Overview | Multimorbidity | Quality standards | NICE. Retrieved April 6, 2020, from https://www.nice.org.uk/guidance/qs153

Naylor, C., Das, P., Ross, S., Honeyman, M., Thompson, J., & Gilburt, H. (2016). Bringing together physical and mental health A new frontier for integrated care.

Naylor, C., Parsonage, M., Mcdaid, D., Knapp, M., Fossey, M., & Galea, A. (2012). Long-term conditions and mental health The cost of co-morbidities.

Neff, K. D. (2011). Self-Compassion, Self-Esteem, and Well-Being. *Social and Personality Psychology Compass*, *5*, 1–12. https://doi.org/10.1111/j.1751-9004.2010.00330.x

Neufeld, S. A. S., Sikkema, K. J., Lee, R. S., Kochman, A., & Hansen, N. B. (2012). The Development and Psychometric Properties of the HIV and Abuse Related Shame Inventory (HARSI). *AIDS and Behavior*, *16*, 1063–1074. https://doi.org/10.1007/s10461-011-0086-9

NHS Digital. (n.d.). Supporting Information: Long Term Physical Health Condition. Retrieved June 26, 2020, from https://www.datadictionary.nhs.uk/data_dictionary/nhs_business_definitions/l/long_term_physical_health_condition_de.asp?shownav=1

Ohrnberger, J., Fichera, E., & Sutton, M. (2017). The relationship between physical and mental health: A mediation analysis. *Social Science and Medicine*, *195*, 42–49. https://doi.org/10.1016/j.socscimed.2017.11.008

Parker, R. I., Vannest, K. J., & Davis, J. L. (2011). Effect size in single-case research: a review of nine nonoverlap techniques. *Behavior Modification*, *35*(4), 303–322. https://doi.org/10.1177/0145445511399147

Parker, R. I., Vannest, K. J., Davis, J. L., & Sauber, S. B. (2011). Combining Nonoverlap and Trend for Single-Case Research: Tau-U. *Behavior Therapy*, *42*(2), 284–299. https://doi.org/10.1016/j.beth.2010.08.006

Persons, E., Kershaw, T., Sikkema, K. J., & Hansen, N. B. (2010). The Impact of Shame on Health-Related Quality of Life Among HIV-Positive Adults with a History of Childhood Sexual Abuse. *AIDS Patient Care and STDs*, *24*(9), 571–580. https://doi.org/10.1089/apc.2009.0209

Pila, E., Sabiston, C. M., Castonguay, A. L., Arbour-Nicitopoulos, K., & Taylor, V. H. (2018). Mental health consequences of weight cycling in the first-year post-treatment for breast cancer. *Psychology & Health*, *33*(8), 995–1013. https://doi.org/10.1080/08870446.2018.1453510

Renn, B. N., Feliciano, L., & Segal, D. L. (2011, December 1). The bidirectional relationship of depression and diabetes: A systematic review. *Clinical Psychology Review*. Pergamon. https://doi.org/10.1016/j.cpr.2011.08.001

Ritter, P. L., & Lorig, K. (2014). The English and Spanish Self-Efficacy to Manage Chronic Disease Scale measures were validated using multiple studies. *Journal of Clinical Epidemiology*, *67*(11), 1265–1273. https://doi.org/10.1016/j.jclinepi.2014.06.009

Roman, N. V, & Frantz, J. M. (2013). The prevalence of intimate partner violence in the family: a systematic review of the implications for adolescents in Africa. *Family practice,* 30(3), 256-265 https://doi.org/10.1093/fampra/cms084

Royal College of Psychiatrists. (2013). *Liaison psychiatry for every acute hospital* . London.

Rudich, Z., Lerman, S. F., Gurevich, B., Weksler, N., & Shahar, G. (2008). Patients' Self-Criticism Is a Stronger Predictor of Physician's Evaluation of Prognosis Than Pain Diagnosis or Severity in Chronic Pain Patients. *Journal of Pain*, *9*(3), 210–216. https://doi.org/10.1016/j.jpain.2007.10.013

Scottish Government. (2015a). Long Term Conditions. Retrieved June 5, 2018, from http://www.gov.scot/Topics/Health/Services/Long-Term-Conditions

Scottish Government. (2015b). *The Matrix (2015) A Guide to Delivering Evidence-Based Psychological Therapies in Scotland*.

Sharpe, L., & Curran, L. (2006). Understanding the process of adjustment to illness. *Social Science & Medicine*, *62*, 1153–1166. https://doi.org/10.1016/j.socscimed.2005.07.010

Sikkema, K. J., Hansen, N. B., Meade, C. S., Kochman, A., & Fox, A. M. (2009). Psychosocial predictors of sexual HIV transmission risk behavior among HIV-positive adults with a sexual abuse history in childhood. *Archives of Sexual Behavior*, *38*(1), 121–134. https://doi.org/10.1007/s10508-007-9238-4

Sirois, F. M., Molnar, D. S., & Hirsch, J. K. (2015). Self-Compassion, Stress, and Coping in the Context of Chronic Illness. *Self and Identity*, *14*(3), 334–347. https://doi.org/10.1080/15298868.2014.996249

Sirois, F. M., Rowse, G., & Review, D. C. (2016). *The Role of Self-Compassion in Chronic Illness Care*. *www.jcomjournal.com* (Vol. 23).

Taal, L. A., & Faberb, A. W. (1998). Posttraumatic stress and maladjustment among adult burn survivors l-2 years postburn. *Burns* (Vol. 24).

Taal, L., & Faber, A. W. (1998). Posttraumatic stress and maladjustment among adult burn survivors 1 to 2 years postburn Part II: *the interview data*. *Burns* (Vol. 24).

Takahashi, H., Yahata, N., Koeda, M., Matsuda, T., Asai, K., Okubo, Y., & Hospital, A. (2004). Brain activation associated with evaluative processes of guilt and embarrassment: an fMRI study. *Neuroimage,* 23(3), 967-974 https://doi.org/10.1016/j.neuroimage.2004.07.054

Tangney, J. P., Miller, R. S., Flicker, L., & Barlow, D. H. (1996). Are shame, guilt, and

embarrassment distinct emotions? *Journal of Personality and Social Psychology*, *70*(6), 1256–1269. https://doi.org/10.1037//0022-3514.70.6.1256

Tennant, R., Hiller, L., Fishwick, R., Platt, S., Joseph, S., Weich, S., … Stewart-Brown, S. (2007). Health and Quality of Life Outcomes The Warwick-Edinburgh Mental Well-being Scale (WEMWBS): development and UK validation. https://doi.org/10.1186/1477-7525-5-63

Thomas, K. H., Martin, R. M., Potokar, J., Pirmohamed, M., & Gunnell, D. (2014). Reporting of drug induced depression and fatal and non-fatal suicidal behaviour in the UK from 1998 to 2011. *BMC Pharmacology and Toxicology*, *15*(1), 54. https://doi.org/10.1186/2050-6511-15-54

Tirch, D., Schoendorff, B., & Silberstein, L. . (2014). *The ACT Practitioner's Guide to the Science of Compassion: Tools for fostering psychological flexibility*. New Harbringer Publications, Inc.

Tracy, J., Robins, R., & Tangney, J. (2007). *The Self-conscious Emotions: Theory and Research* . Guildford Press.

Trindade, I. A., Duarte, J., Ferreira, C., Coutinho, M., & Pinto-Gouveia, J. (2018). The impact of illness-related shame on psychological health and social relationships: Testing a mediational model in students with chronic illness. *Clinical Psychology & Psychotherapy*, *25*(3), 408–414. https://doi.org/10.1002/cpp.2175

Trindade, I. A., Ferreira, C., & Pinto-Gouveia, J. (2017a). Chronic Illness-Related Shame: Development of a New Scale and Novel Approach for IBD Patients' Depressive Symptomatology. *Clinical Psychology and Psychotherapy*, *24*(1), 255–263. https://doi.org/10.1002/cpp.2035

Trindade, I. A., Ferreira, C., & Pinto-Gouveia, J. (2017b). Chronic Illness-Related Shame: Development of a New Scale and Novel Approach for IBD Patients' Depressive Symptomatology. *Clinical Psychology & Psychotherapy*, *24*(1), 255–263.

https://doi.org/10.1002/cpp.2035

Trindade, I. A., Irons, C., Ferreira, C., Portela, F., & Pinto-Gouveia, J. (2019). The influence of self-criticism on depression symptoms among ambulatory patients with inflammatory bowel disease. *Clinical Psychology & Psychotherapy*, *26*(6), 743–750. https://doi.org/10.1002/cpp.2398

Trindade, I. A., Marta-Simões, J., Ferreira, C., & Pinto-Gouveia, J. (2018). Developments on committed action: Validity of the CAQ-8 and analysis of committed action's role in depressive symptomatology in breast cancer patients and healthy individuals. *Clinical Psychology and Psychotherapy*, *25*(1), e42–e50. https://doi.org/10.1002/cpp.2125

Trindade, I. A., Marta-Simões, J., Ferreira, C., & Pinto-Gouveia, J. (2018). Chronic illness-related cognitive fusion explains the impact of body dissatisfaction and shame on depression symptoms in breast cancer patients. *Clinical Psychology & Psychotherapy*, *25*(6), 886–893. https://doi.org/10.1002/cpp.2323

Trindade, I., Ferreira, C., & Pinto-Gouveia, J. (2017). Shame and emotion regulation in inflammatory bowel disease: Effects on psychosocial functioning. *Journal of Health Psychology* (0), 1–11. https://doi.org/10.1177/1359105317718925

Vannest, K.J., Parker, R.I., Gonen, O., & Adiguzel, T. (2016). Single Case Research: web based calculators for SCR analysis. (Version 2.0) [Web-based application]. College Station, TX: Texas A&M University. Retrieved Thursday 30th April 2020. Available from singlecaseresearch.org

Vincent, W., Fang, X., Calabrese, S. K., Heckman, T. G., Sikkema, K. J., & Hansen, N. B. (2017). HIV-related shame and health-related quality of life among older, HIV-positive adults. *Journal of Behavioral Medicine*, *40*(3), 434–444. https://doi.org/10.1007/s10865-016-9812-0

Werner, A., Isaksen, L. W., & Malterud, K. (2004). "I am not the kind of woman who

complains of everything": Illness stories on self and shame in women with chronic pain. *Social Science and Medicine*, *59*(5), 1035–1045. https://doi.org/10.1016/j.socscimed.2003.12.001

Wiechelt, S. A. (2017). Substance Use & Misuse The Specter of Shame in Substance Misuse. *Substance Use & Misuse*, *42*(2-3), 399-409. https://doi.org/10.1080/10826080601142196

Wong, W. C. W., Cheung, C. S. K., & Hart, G. J. (2008). Development of a quality assessment tool for systematic reviews of observational studies (QATSO) of HIV prevalence in men having sex with men and associated risk behaviours. *Emerging Themes in Epidemiology*. BioMed Central. https://doi.org/10.1186/1742-7622-5-23

Wren, A. A., Somers, T. J., Wright, M. A., Goetz, M. C., Leary, M. R., Fras, A. M., … Keefe, F. J. (2012). Self-Compassion in Patients With Persistent Musculoskeletal Pain: Relationship of Self-Compassion to Adjustment to Persistent Pain. *Journal of Pain and Symptom Management*, *43*, 759–770. https://doi.org/10.1016/j.jpainsymman.2011.04.014

Yakeley, J. (2018). Shame, culture and mental health. *Nordic Journal of Psychiatry*, *72*(sup1), S20–S22. https://doi.org/10.1080/08039488.2018.1525641

Yalom, I. D., & Leszcz, M. (2005). *The theory and practice of group psychotherapy*. Basic Books.

Appendices

Table of Appendices Page

1	References of studies with a global measure of shame	100
2	Rebalance weekly battery scores	103
3	Protocol	109
4	Participant information sheet and consent form	132
5	Ethical approval	136
6	Author guidelines for Journal of Behavioral Medicine	140

Appendix One: References of studies with a global measure of shame

Bricker, J. B., Watson, N. L., Heffner, J. L., Sullivan, B., Mull, K., Kwon, D., ... & Ostroff, J. (2020). A Smartphone App Designed to Help Cancer Patients Stop Smoking: Results From a Pilot Randomized Trial on Feasibility, Acceptability, and Effectiveness. *JMIR Formative Research*, *4*(1), e16652.

Burgener, S. C., & Berger, B. (2008). Measuring perceived stigma in persons with progressive neurological disease: Alzheimer's dementia and Parkinson's disease. Dementia, 7(1), 31-53.

Cantisano, N., Rimé, B., Afzali, M. H., & Munoz-Sastre, M. T. (2016). Health outcomes resulting from the quality of emotional expression in HIV/AIDS patients. *European Review of Applied Psychology*, *66*(3), 95-100.

Cantisano, N., Rimé, B., & Teresa Munoz Sastre, M. (2015). The importance of quality over in quantity in the social sharing of emotions (SSE) in people living with HIV/AIDS. *Psychology, health & medicine*, *20*(1), 103-113

Dirkse, D., Lamont, L., Li, Y., Simonič, A., Bebb, G., & Giese–Davis, J. (2014). Shame, guilt, and communication in lung cancer patients and their partners. *Current Oncology*, *21*(5), e718.

Ernst, J., Mehnert, A., Dietz, A., Hornemann, B., & Esser, P. (2017). Perceived stigmatization and its impact on quality of life-results from a large register-based study including breast, colon, prostate and lung cancer patients. *BMC cancer*, 17(1), 741.

Fife, B. L., & Wright, E. R. (2000). The dimensionality of stigma: A comparison of its impact on the self of persons with HIV/AIDS and cancer. *Journal of health and social behavior*, 50-67.

Gonzalez, B. D., Jim, H. S., Cessna, J. M., Small, B. J., Sutton, S. K., & Jacobsen, P. B. (2015). Concealment of lung cancer diagnosis: prevalence and correlates. *Psycho-Oncology*, *24*(12), 1774-1783.

Harrison, S. L., Robertson, N., Goldstein, R. S., & Brooks, D. (2017). Exploring self-conscious emotions in individuals with chronic obstructive pulmonary disease: a mixed-methods study. *Chronic respiratory disease*, *14*(1), 22-32.

Jahanzad, S., Hassani, F., Ghanbaripanah, A., & Zahedmehr, A. (2018). Determining the psychometric properties of early maladaptive schemas test in patients with coronary heart disease and comparing them with the ones in healthy individuals. Annals of Tropical Medicine and Public Health, 16, S13414

Kissane, D. W., Patel, S. G., Baser, R. E., Bell, R., Farberov, M., Ostroff, J. S., ... & Shah, J. P. (2013). Preliminary evaluation of the reliability and validity of the Shame and Stigma Scale in head and neck cancer. *Head & neck*, *35*(2), 172-183.

Landau, G., & York, A. S. (2004). Keeping and disclosing a secret among people with HIV in Israel. *Health & Social Work*, 29(2), 116-126.

Li, L., Lee, S. J., Thammawijaya, P., Jiraphongsa, C., & Rotheram-Borus, M. J. (2009). Stigma, social support, and depression among people living with HIV in Thailand. *AIDS care*, *21*(8), 1007-1013.

LoConte, N. K., Else-Quest, N. M., Eickhoff, J., Hyde, J., & Schiller, J. H. (2008). Assessment of guilt and shame in patients with non–small-cell lung cancer compared with patients with breast and prostate cancer. *Clinical lung cancer*, *9*(3), 171-178.

Nejatisafa, A. A., Mozafari, S., Noorbala, A. A., Asgarian, F. S., Earnshaw, V. A., Sahraian, M. A., & Etesam, F. (2017). Psychometric Evaluation of the Persian Version of the Chronic Illness Anticipated Stigma Scale (CIASS). *International journal of behavioral medicine*, *24*(4), 634-640

Phillips, K., Wright, B. J., & Kent, S. (2013). Psychosocial predictors of irritable bowel syndrome diagnosis and symptom severity. *Journal of psychosomatic research*, 75(5), 467-474.

Pirola, W. E., Paiva, B. S. R., de Oliveira, C. Z., Lucchetti, G., Lucchetti, A. L. G., Kissane, D., & Paiva, C. E. (2019). Validation of the Brazilian version of the Shame and Stigma Scale (SSS-Br) for patients with head and neck cancers. *Palliative & supportive care*, 1-7.

Poku, K. A., Linn, J. G., Fife, B. L., Azar, S., & Kendrick, L. (2005). A comparative analysis of perceived stigma among HIV-positive Ghanaian and African American males. SAHARA-J: *Journal of Social Aspects of HIV/AIDS*, 2(3), 344-351.

Tseng, W. T., Lee, Y., Hung, C. F., Lin, P. Y., Chien, C. Y., Chuang, H. C., ... & Wang, L. J. (2019). Validation of the Chinese Version of the Shame and Stigma Scale in Patients with Head and Neck Cancer. *Cancer Management and Research*, *11*, 10297.

Turner-Cobb, J. M., Michalaki, M., & Osborn, M. (2015). Self-conscious emotions in patients suffering from chronic musculoskeletal pain: A brief report. *Psychology & health*, *30*(4), 495-501

von Ranson, K. M., Stevenson, A. S., Cannon, C. K., & Shah, W. (2010). Changes in eating pathology and associated symptoms among chronically ill adults attending a brief psychoeducational group. *Eating behaviors*, 11(3), 186-189.

Wertheim, R., Hasson-Ohayon, I., Mashiach-Eizenberg, M., Pizem, N., Shacham-Shmueli, E., & Goldzweig, G. (2018). Hide and “sick”: Self-concealment, shame and distress in the setting of psycho-oncology. *Palliative & supportive care*, *16*(4), 461-469.

Williams, S. L., Fekete, E. M., & Skinta, M. D. (2019). Self-Compassion in PLWH: Less Internalized Shame and Negative Psychosocial Outcomes. *Behavioral Medicine*, 1-9.

Yuan, J. M., Zhang, J. E., Zheng, M. C., & Bu, X. Q. (2018). Stigma and its influencing factors among Chinese patients with stoma. *Psycho-oncology*, *27*(6), 1565-1571.

Zhang, M. J., Mu, J. W., Chen, X. R., Zhang, X., & Feng, C. (2018). Effect of voice rehabilitation training on the patients with laryngeal cancer after radiotherapy. *Medicine*, *97*(26).

Appendix Two – Weekly battery scores

Participant one – weekly battery scores

Measure	Session of intervention										
	Baseline	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
CEAS: to self	55	41	63	39	50	-	50	55	-	57	56
CEAS: to others	75	75	83	66	80	-	76	79	-	82	77
CEAS: from others	54	57	51	52	57	-	49	66	-	60	62
WASA	19	24	27	23	27	-	26	27	-	31	26
SE	2.17	2.5	1	1.83	1.17	-	1	1.67	-	1	1
ICQ: helplessness	12	17	17	15	20	-	19	16	-	14	13
ICQ: acceptance	9	10	7	9	7	-	6	7	-	6	6
ICQ: Perceived benefit	6	6	6	6	6	-	6	6	-	6	6
WEMWBS	21	23	21	29	25	-	24	23	-	28	31

Participant Two – weekly battery scores

Measure	Session of intervention										
	Baseline	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
CEAS: to self	49	63	71	69	-	67	-	-	-	69	-
CEAS: to others	63	69	65	62	-	52	-	-	-	62	-
CEAS: from others	78	79	71	67	-	64	-	-	-	63	-
WASA	26	20	16	19	-	13	-	-	-	19	-
SE	2.83	5	5.33	4.5	-	3.83	-	-	-	5.33	-
ICQ: helplessness	19	13	15	14	-	13	-	-	-	15	-
ICQ: acceptance	13	14	10	13	-	12	-	-	-	14	-
ICQ: Perceived benefit	21	19	20	21	-	22	-	-	-	17	-
WEMWBS	30	39	38	37	-	42	-	-	-	35	-

Participant Three – weekly battery scores

Measure	Session of intervention										
	Baseline	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
CEAS: to self	57	53	56	55	55	62	61	57	59	61	-
CEAS: to others	94	89	81	81	84	70	76	68	69	70	-
CEAS: from others	86	67	68	64	70	69	78	68	68	76	-
WASA	32	34	35	35	34	33	42	34	35	34	-
SE	2	2	2.5	1.83	2.67	1.5	2	2.83	3.17	3.17	-
ICQ: helplessness	24	24	24	24	24	24	24	23	24	24	-
ICQ: acceptance	6	6	6	6	6	6	6	6	6	6	-
ICQ: Perceived benefit	9	9	7	9	7	8	8	7	7	7	-
WEMWBS	43	46	39	42	47	44	44	45	43	44	-

Participant Four – weekly battery scores

Measure	Session of intervention										
	Baseline	*2*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
CEAS: to self	28	22	22	-	28	27	-	36	-	-	48
CEAS: to others	93	92	100	-	93	94	-	96	-	-	85
CEAS: from others	59	39	52	-	37	47	-	40	-	-	43
WASA	34	25	19	-	22	21	-	19	-	-	22
SE	8.33	5.33	8.67	-	7.33	7.17	-	7.33	-	-	7.67
ICQ: helplessness	19	18	15	-	13	15	-	16	-	-	12
ICQ: acceptance	14	17	16	-	17	16	-	17	-	-	21
ICQ: Perceived benefit	22	24	24	-	24	24	-	23	-	-	24

WEMWBS	40	28	31	-	24	41	-	47	-	-	44

Participant Five – weekly battery results

Measure	Session of intervention										
	Baseline	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
CEAS: to self	51	48	50	43	50	52	60	67	-	74	74
CEAS: to others	78	71	65	67	53	58	61	67	-	76	76
CEAS: from others	75	66	53	68	65	62	59	67	-	76	76
WASA	13	11	15	13	14	16	15	5	-	8	12
SE	6.83	6.5	5.83	6.17	5.5	4.67	5.33	6.67	-	7.5	7.67

ICQ: helplessness	11	13	13	12	14	12	11	11	-	10	14
ICQ: acceptance	16	11	13	14	13	14	13	16	-	16	18
ICQ: Perceived benefit	8	10	9	8	6	9	10	11	-	14	15
WEMWBS	33	39	34	38	32	37	33	38	-	46	39

Table six – weekly battery scores

Measure	Session of Intervention										
	Baseline	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
CEAS: to self	54	65	70	77	72	66	-	-	-	80	84

CEAS: to others	65	61	75	86	77	79	-	-	-	79	84
CEAS: from others	70	64	75	74	81	74	-	-	-	79	78
WASA	16	16	14	12	14	12	-	-	-	14	13
SE	5.5	4	5.5	4.67	4.33	5.17	-	-	-	3.67	4.17
ICQ: helplessness	12	15	14	12	14	12	-	-	-	11	11
ICQ: acceptance	13	14	14	14	18	15	-	-	-	15	16
ICQ: Perceived benefit	17	21	20	19	20	19	-	-	-	18	18
WEMWBS	41	43	46	41	45	39	-	-	-	53	41

Appendix Three – Study Protocol

Study Protocol

Group Compassion Focussed Therapy for people with transdiagnostic chronic health conditions – a case series

	The University of Edinburgh and Lothian Health Board ACCORD The Queen's Medical Research Institute 47 Little France Crescent Edinburgh EH16 4TJ	
Protocol authors	**Anna Maddison**	
Chief Investigator	**Anna Maddison**	
Sponsor number	CAHSS1810/04	
REC Number	**18/SS/0164**	
Project registration	**To be registered on clinicaltrials.gov as an observational study.**	
Version Number and Date	**V3.0 11/07/2019**	

Amendment classification and number: Substantial 11th July 2019	Summary of change(s) Addition to recruitment and consent process.

CONTENTS

1 INTRODUCTION 119

1.1 BACKGROUND 119

1.2 RATIONALE FOR STUDY 123

2 STUDY OBJECTIVES 124

2.1 OBJECTIVES 124

2.1.1 Primary Objective 124

2.1.2 Secondary Objectives 124

2.2 ENDPOINTS 124

2.2.1 Primary Endpoint 124

2.2.2 Secondary Endpoints 124

3 STUDY DESIGN 125

4 STUDY POPULATION 125

4.1 NUMBER OF PARTICIPANTS 125

4.2 INCLUSION CRITERIA 125

4.3 EXCLUSION CRITERIA 125

4.4 CO-ENROLMENT 126

4.5 IDENTIFYING PARTICIPANTS 126

4.6 CONSENTING PARTICIPANTS 126

4.6.1 Withdrawal of Study Participants 127

5 STUDY ASSESSMENTS 128

5.1 STUDY ASSESSMENTS 128

5.2 LONG TERM FOLLOW UP ASSESSMENTS 129

6 DATA COLLECTION 130

6.1 Source Data Documentation 130

7 STATISTICS AND DATA ANALYSIS 131

7.1 SAMPLE SIZE CALCULATION 131

7.2 PROPOSED ANALYSES 131

8 RISKS **Error! Bookmark not defined.**

9 OVERSIGHT ARRANGEMENTS 132

9.1 INSPECTION OF RECORDS 132

9.2 RISK ASSESSMENT 132

9.3 STUDY MONITORING AND AUDIT 132

The ACCORD Sponsor Representative will assess the study to determine if an independent risk assessment is required. If required, the independent risk assessment will be carried out by the ACCORD Quality Assurance Group to determine if an audit should be performed before/during/after the study and, if so, at what frequency. 132

10 GOOD CLINICAL PRACTICE 133

10.1 ETHICAL CONDUCT 133

Before the study can commence, all required approvals will be obtained and any conditions of approvals will be met. 133

10.2 INVESTIGATOR RESPONSIBILITIES 133

10.2.1 Informed Consent 133

10.2.2 Study Site Staff 134

10.2.3 Data Recording 134

10.2.4 Investigator Documentation 134

10.2.5 GCP Training 134

10.2.6 Confidentiality 134

10.2.7 Data Protection 135

11 STUDY CONDUCT RESPONSIBILITIES 135

11.1 PROTOCOL AMENDMENTS 135

11.2 MANAGEMENT OF PROTOCOL NON COMPLIANCE 136

11.3 SERIOUS BREACH REQUIREMENTS 136

11.4 STUDY RECORD RETENTION 137

11.5 END OF STUDY 137

11.6 CONTINUATION OF TREATMENT FOLLOWING THE END OF STUDY 137

11.7 INSURANCE AND INDEMNITY 137

12 REPORTING, PUBLICATIONS AND NOTIFICATION OF RESULTS 138

12.1 AUTHORSHIP POLICY 138

13 REFERENCES 138

LIST OF ABBREVIATIONS

ACCORD	Academic and Clinical Central Office for Research & Development - Joint office for The University of Edinburgh and Lothian Health Board
CI	Chief Investigator
CRF	Case Report Form
CFT	Compassion Focussed Therapy
GCP	Good Clinical Practice
ICH	International Conference on Harmonisation
LTC	Long Term Condition
PI	Principal Investigator
QA	Quality Assurance
REC	Research Ethics Committee
SOP	Standard Operating Procedure

INTRODUCTION

BACKGROUND

Living with long term health conditions

The relationship between physical and mental health is bi-directional and reciprocally damaging. The presence of either increases the likelihood of the other, leading to a negative cycle of increasingly complex and severe psychological and physiological ill-health (Naylor et al., 2012).

Long-term health conditions (LTCs), also known as chronic health conditions can be described as physical illness which cannot currently be cured, affects a person's life and requires ongoing

management e.g. cardiovascular disease, respiratory disease, arthritis and diabetes (Scottish Government, 2015a). Around 40% of the Scottish population have at least one long term health condition. Other conditions which fit this description include those in which symptomology has no clear physiological cause e.g. IBS or had a clear trigger which has now resolved but with lasting effect e.g. traumatic injury leading to chronic pain.

Living with a chronic health condition brings about significant psychological challenges. At the time of diagnosis patients can experience a sense of loss for the life they had planned, apprehension regarding treatment, and uncertainty regarding the future. With time, the implications of living with a chronic health condition e.g. complex medication regimens, deteriorating physical abilities and social functioning difficulties, become salient and patients can vary in their ability to adjust to their circumstances. Furthermore, the medication prescribed for physical health conditions can also be detrimental to psychological well-being (Thomas et al, 2014). Given the implications across social, psychological and physiological domains, it is not surprising that people with chronic illness are two to three times more likely to experience mental ill-health than the general population (Naylor et al., 2012). As the number of physical health co-morbidities increase, so too does the risk of a mental health problem. For the NHS there is a significantly increased cost in the management of patients with co-morbid psychological difficulties and LTCs (Naylor et al., 2012).

The role of adjustment

Psychiatric definition of adjustment traditionally involves the presence or absence of psychopathology in relation to an identified stressor. This definition would make the construct of adjustment easy to both define and measure. However, it lacks the complexity and depth of the meaning of adjustment used in clinical health psychology. Here adjustment has been considered both a process and a desirable outcome, those who adjust well demonstrate positive affect, adaptive social and physical functioning. As such, poor adjustment can still be seen in those who do not experience clinical levels of psychopathology (Moss-Morris, 2013). It has previously been operationalised as good quality of life (QoL), wellbeing, vitality, positive affect, life satisfaction and self-esteem. However, these constructs are used to both predict and indicate good adjustment, evading a clear

definition. Multiple theories and models have been proposed to clarify the process of adjustment however there is variation in the order of constructs, and the relative emphasis upon certain elements e.g. stress, illness perception, cognition, behaviour, self-efficacy and emotion regulation (Dekker & de Groot, 2018). Diversity in the definition and constructs of adjustment confound the design, methodology and measurement of comparable research.

Throughout the literature, factors identified as important to adjustment include: ongoing illness stressors; emotional, cognitive and behavioural responses; personal background and; social and environmental background (Dekker & de Groot, 2018). Adaptive and positive psychological responses in these domains are linked to improved psychological and physical outcomes.

Psychological intervention in physical health

For those with chronic ill health who adjust poorly or present with significant psychological distress relevant to their health condition, psychological intervention is recommended. The Psychological Therapies 'Matrix' (Scottish Government, 2015) contains guidance on sufficiently evidenced psychological interventions recommended for commissioning within services. Collaborative care between physical and mental health services, delivered within a stepped care model is recommended (National Institute of Clinical Excellence, 2009). Low intensity interventions involve self-management of physical wellbeing following a cognitive behavioural approach and include self-regulation processes of goal setting, planning, self-monitoring, feedback and relapse prevention (Scottish Government, 2015b). High intensity therapeutic input is primarily recommended in the form of cognitive behavioural therapy (CBT). Individual, group, computerised and adapted CBT have each been evidenced within various chronic health conditions in reducing anxiety and depression and increasing self-management (Scottish Government, 2015).

The theory upon which CBT draws lends itself to designing interventions that promote adjustment. Using a cognitive model of thoughts, emotions and behaviours patients can be facilitated in gaining knowledge and skills to understand and change their maladaptive cognitions, behaviours and coping strategies. Change within these domains is linked to factors which contribute to successful adjustment i.e. psychological distress, self-efficacy and social functioning (Dekker & de Groot, 2018). However, there are limits to the application of CBT.

The theoretical basis is disorder specific, with each disorder characterised by its own set of thought distortions and biased processes. Within LTC populations this can leave significant gaps in the coverage of distress. Often patterns of cognition, behaviour and affect in such populations include transdiagnostic factors, aspects of multiple psychopathologies and distress related specifically to the health condition (British Psychological Society, 2008). Further, not all cognitions are distorted in LTCs, rather the way in which accurate thoughts about illness are related to which causes emotional and behavioural consequences. Therefore, a CBT model may not generalise to cover the breadth of distress experienced in LTC populations.

Compassion Focussed Therapy (CFT)

Compassion Focused Therapy (CFT) is a third wave psychological therapy with cognitive behavioural routes. It focuses on shame, self-criticism and developing compassion. In this context compassion entails the twin psychologies of sensitivity to the suffering of others (affect and cognitions), and the motivation to act to alleviate it (cognition and behaviour) (Gilbert, 2014). Drawing from evolutionary, social, developmental, Buddhist psychology, and neuroscience, CFT aims to develop: care for well-being; sensitivity; distress tolerance; sympathy; empathy and; non-judgement (Cuppage, Baird, Gibson, Booth, & Hevey, 2018; Kolts, 2016). These key attributes of compassion are developed by learning and practicing skills in attention, imagery, behaviour, reasoning and emotion (Paul Gilbert, 2014; Leaviss & Uttley, 2015). Increasing compassion has been shown to have numerous positive impacts upon cognitive, affective and psychological well-being (Zessin, Dickhäuser, & Garbade, 2015). Those higher in compassion report better mental health, resilience and emotion regulation (Inwood & Ferrari, 2018; MacBeth & Gumley, 2012b). There is growing evidence for the efficacy of CFT in numerous presentations including depression, anxiety, eating disorders, psychosis and personality disorder (Kolts, 2016) delivered as both one-to-one and group therapy (Paul Gilbert & Procter, 2006; Judge, Cleghorn, McEwan, & Gilbert, 2012). Whilst this body of literature is relatively young it shows promise for the efficacy of treatment and gives base for further research to be undertaken.

Research shows people with LTCs present with higher levels of shame and self-criticism. They have been linked to increased distress in multiple long term health conditions including acquired brain injury, diabetes, HIV, multiple sclerosis and somatoform disorders (Ashworth, Clarke, Jones, Jennings, & Longworth, 2014; Brion,

Leary, & Drabkin, 2014; Dewsaran-van der Ven et al., 2018; Friis et al, 2016) These can stem from negative emotions relating to the process and consequences of illness onset, symptomology, diagnosis, current bio-psycho-social functioning and illness management.

There is a dearth of high quality, large scale research in populations with long term health conditions. However, evidence is beginning to cumulate which indicates moderate effect sizes for CFT relating to decreased distress and increased psychological wellbeing and self-management (Kirby, Tellegen, & Steindl, 2017).

RATIONALE FOR STUDY

Whilst there are logical reasons for the use of CBT in LTCs, limitations remain regarding its cognitive and disorder specific focus. As high levels of shame and self-criticism are reported in LTCs there is potential for the efficacious use of CFT.

This research will begin to evaluate a novel group CFT intervention for people with significant psychological distress related to one or more long term health conditions, with the aim of improving adjustment. Novelty arises in that group includes transdiagnostic physical and mental health difficulties, which traditionally would be grouped by disorder for intervention. This intervention acknowledges that despite varied underlying health conditions, the psycho-social presentations of individuals attending are broadly similar and complex i.e. disrupted social functioning, maladaptive behavioural patterns (e.g. avoidance), negative affect, psychological distress and emotion dysregulation. All individuals invited to attend this group present with high levels of self-criticism and difficulty in self-compassion, as well as eliciting and accepting compassion from others.

The group arose as a recent service development, designed and facilitated by two Clinical Health Psychologists trained in CFT. The content of the group was developed iteratively following two previous cohorts. There are nine-weekly sessions, eight of which last 2.5 hours and following a three-part structure: 1) Thinking (reflections on participants' experiences, including concepts and techniques learned in the previous week); 2) New Ideas (concepts from the CFT model); 3) New Tools (explanation and practice of psychological and behavioural techniques). The ninth session occurs in the middle of the intervention and involves a one-to-one with a group

facilitator to check in with understanding, progress and any concerns either participants or facilitator may have.

The study brings benefit to services by offering detailed insight of changes in adjustment throughout the intervention. This will allow the service to demonstrate efficacy of intervention, allowing further roll out. It also begins to gather evidence for the use of CFT within health populations in promoting adjustment to LTCs.

STUDY OBJECTIVES

OBJECTIVES

Primary Objective

The primary objective of this study is to test the individual effectiveness of compassion focussed therapy (CFT) delivered as a group intervention for people with various and/or multiple long term health conditions, in promoting positive adjustment to LTC.

Secondary Objectives

To track the process of change across time in each domain that comprises adjustment, in response to session content.

ENDPOINTS

Primary Endpoint

The primary endpoint is completion of the battery at the final week of the group intervention.

Secondary Endpoints

Participants are routinely followed up at 3 months post-intervention by the service. At this point they will be asked to complete the full battery and individuals who have received no further input from psychology services will be invited to complete daily data collection for a ten day period. The service may choose to send the battery to all service users, including participants of this study who have attended the Rebalance group at 3 months after the group end date.

STUDY DESIGN

The study will use a single case experimental design, case series methodology. Multiple baselines will be used varying the length of participant involvement from 10 weeks and 3 days, to 11 weeks. Recruitment and weekly data collection (battery) will occur in the NHS Lothian Clinical Health Psychology department at the Astley Ainslie Hospital. The three daily questions will be completed by participants in their own time each day and the paper diaries collected each week in the department. Data from up two cohorts of the group will aim to be collected over a 9 month period.

STUDY POPULATION

NUMBER OF PARTICIPANTS

Small scale design foregoes external validity to achieve high internal validity, therefore features of randomisation of baseline and number of data points per phase are highly relevant. Each case is a form of representation of the last, as such, this study will aim for between 8 to 12 cases with a minimum of 6. All participants will be adults accessing Clinical Health Psychology in NHS Lothian who have been referred to, and agree to attend the Rebalance group intervention. Recruitment and participation will occur on one site, this will be a rolling process over a 12 month period as the groups run throughout the year.

INCLUSION CRITERIA

Experiencing difficulties adjusting to one or more chronic physical health condition(s)

Willing and motivated to attend a nine-week group facilitated in English

Exhibit sufficient interpersonal skills and impulse control to allow them to engage with group members without disrupting group dynamics

Able to provide informed consent

EXCLUSION CRITERIA

Moderate or severe impairment of cognitive function

Primary problem related to drug or alcohol misuse

Actively suicidal or experiencing an acute deterioration in their mental health including experiencing an acute psychotic episode

CO-ENROLMENT

Participants will not be able to co-enrol in any other health related (medical or psychology) studies. This will be made clear in the participant information form. It will be confirmed with participants that they are not currently partaking in other research at the time of giving informed consent. This will be recorded alongside their demographic information in the data set.

IDENTIFYING PARTICIPANTS

Participants will be identified by clinical staff working with individuals. If they assess a patient as part of the Clinical Health Psychology service, and recommend attending Rebalance, each individual will be given a participant information sheet and asked if they can be contacted by the researcher.

CONSENTING PARTICIPANTS

Participants will be given the information sheet when placed on the Rebalance waiting list as part of their routine care. If they are already waiting to attend the group when the project commences, they will be contacted by their referring clinician, a group facilitator or an assistant psychologist within the service to give an overview of the project. The information sheet will then be sent only to those who are interested in hearing more about the study. Potential participants will be permitted a minimum of 24 hours to consider the information before being contacted by the researcher, consenting will then occur at an arranged meeting prior to baseline collection. They will have the opportunity to ask any questions about partaking in the research both during initial telephone call and at arranged meeting. If participants are unable to attend a meeting prior to commencing baseline collection, due to their illness or commitments, the researcher will discuss the consent form thoroughly, gain verbal consent to participate, and ask participants to sign the consent form they

received with the information sheet. The participants will then complete baseline data collection and bring the signed consent form to the first group session. The principal investigator, assistant psychologist or group facilitator will phone each participant the day before the group to ensure they bring the consent form to the session.

Informed consent will predominately be gained by the principal investigator. It may also be gained by clinicians who are facilitating the group, or the service's assistant psychologist, with appropriate training and a consent checklist for clinicians to use to ensure all items are covered.

Withdrawal of Study Participants

Participants are free to withdraw from the study at any point or a participant can be withdrawn by the Investigator. If withdrawal occurs, the primary reason for withdrawal will be documented in participant information log and GP will be informed. The participant will have the option of:

withdrawal from the Rebalance group i.e. declining further intervention.

withdrawal from the research aspect of the Rebalance group but continued attendance at the Rebalance group.

With regards to data collected up to that point, participants are asked to consent to all data collected up to that point being used for analysis.

Potential reasons for a study participant stopping early include but are not limited to:

Drop out from Rebalance group

Perceived burden of data collection

Intermittent attendance at group – if two or more consecutive weeks are missed.

Intermittent adherence to data collection – if less than four days of data is collected per week.

In the situation in which a participant requests to withdraw, they can do so by informing a member of the Rebalance staff i.e. facilitators or administrative staff, or contact the researcher directly. In the situation in which missed sessions or data collection leads to the decision a participant should be withdrawn, the researcher will telephone the participant or meet with them after a group session to discuss this.

STUDY ASSESSMENTS

STUDY ASSESSMENTS

Timetable of assessments throughout intervention:

Time point	*Assessment*	*Format*	*Location*
Baseline	Full battery	Paper hard copies	Astley Ainslie Hospital
Daily from baseline to completion	Three questions	Paper diary	Participants choice – likely their own home
Weekly before intervention	Full battery	Paper hard copies	Astley Ainslie Hospital
Three Month Follow Up	Full Battery	Paper hard copies	Via post
Three Month Follow up (for a period of ten days)	Three questions	Paper diary	Participants choice – likely their own home

Within the full battery assessment includes the following questionnaires:

Compassionate Engagement and Actions Scale (CEAA; (Paul Gilbert et al., 2017): 39 items over three scales 1) Self Compassion, 2) Compassion to others, 3) Compassion from others. Each scale gives two scores, engagement and action, these can be combined to give a total score for each scale, with higher scores indicating higher perceived availability of compassion. All subscales have high internal validity with Chronbachs alpha scores between .74 to .94 (Lindsey, 2017).

Illness Cognitions Questionnaire (ICQ; Evers et al., 2001): 18 items each rated on a four-point scale with high internal validity (all above 0.81. Assessing three domains of perceiving illness (helplessness, acceptance and perceived benefits) this tool identifies maladaptive cognitive styles surrounding illness which are linked to poorer psychological outcomes.

The Warwick-Edinburgh Mental Well-being scale (Tennant et al., 2007): A 14 item measure of psychological wellbeing with high internal validity, with an alpha level 0.91.

Work and Social adjustment scale (WASA; (Mundt et al., 2002). A 5-item measure of functional impairment due to a specified stressor with good internal consistency ranging from 0.70 to 0.94.

Self- efficacy for managing chronic disease scale (Lorig et al., 2001). A 6-item measure of perceived self-efficacy to adherence to recommended self-management programs. Validated within a variety of long term condition populations with a an alpha level of .91 indicating high internal validity.

The three daily questions for completion are scored on a 0-5 Likert scale. The questions are:

How well do you feel you are dealing with the emotional consequences of your health condition today?

How well do you feel you are dealing with the physical consequences of your health condition today?

How able do you feel to talk to yourself with wisdom, strength, warmth and non-judgment today?

LONG TERM FOLLOW UP ASSESSMENTS

As part of routine care participants will receive a review session with the service the week after the last intervention session, this allows patients time to reflect on the intervention and to decide with a clinician if further psychological intervention is required. Routine service follow-up also includes the battery of questionnaires at 3 months following end of intervention. The investigator will have access to outcomes at 1 week and 3 months. As part of the research individuals who have not received any further input from Psychology services at this point, will be invited to complete daily questions for a ten-day period.

DATA COLLECTION

See section 5.1 for timetable of data collection points. Weekly batteries of questionnaires will be collected by the researcher or facilitators prior to the group session beginning each week. It will also be completed with the researcher at the beginning of the baseline period. For details of each questionnaire please see section 5.1. If participants were unable to meet the researcher prior to commencing baseline collection, a telephone call will be made requesting the participant to complete the battery and begin using their daily diary on the appropriate day, and bring these to the first group session.

To maximise completeness of data collection the researcher will discuss with individual participants how best they can maximise likelihood of remembering to fill in the diary each day. Strategies such as leaving the diary somewhere obvious for them, or setting a daily reminder in their phone will be suggested.

All individuals attending the group are sent the dates Rebalance will run. For those participating in this project, their letters will include additional time to complete the weekly battery prior to the group commencing. If participants are not recruited at the time this letter is sent, a telephone call will be made to advise of the start time for the first week, and an updated timetable be provided at this session.

Source Data Documentation

Demographic information: electronic patient records accessed through TRAK with participant consent.

Weekly battery: paper questionnaires completed in the Clinical Health Psychology department.

Daily questions: paper diary with questions and scales on each day. Removable pages to allow for collection each week.

STATISTICS AND DATA ANALYSIS

SAMPLE SIZE CALCULATION

As a case series this research aims to recruit between 8-12 participants with a minimum of 6. It is expected that this is achievable over the course of two Rebalance cohorts. There will therefore be two time periods of recruitment over 9 months. There is flexibility to recruit from a third cohort in addition if required. Recruitment of 12 participants over two cohorts would allow a 50% participation rate. A subsequent dropout rate of 40% would result in 7 completing intervention and full data collection.

PROPOSED ANALYSES

Visual analysis of data will be undertaken and supported by recommended statistical analysis for single case designs. Data points across phases and dependent variables will be plotted into line graphs to visually demonstrate trend, level and stability of data for each case.

Randomisation of baseline will be undertaken prior to commencing intervention. Randomisation tests will then be completed once all data is collected to report validity of results regarding change when intervention is applied. Dependent on visual analysis and the number of outlying data points multiple test statistics of randomisation may be carried out. If there are few outliers, the difference between the (sums of) means for each phase will be used however, comparison of medians or slopes may also be used.

Further analysis will look at the effect size of change for each measure within the battery (see section 5.1) using percentage of non-overlap, with higher percentage indicating larger effect size. Analysis of trend estimation will use the split-middle method as this does not require independence within individuals' data and relies on median values, which are less sensitive to outliers than means.

Data from those who withdraw and whose data contains missing information will be analysed unless the total number of data points would not allow valid analysis (i.e. less than five).

RISKS

The risk level of this study is low. The intervention being investigated is currently care as usual within NHS Lothian. Therefore, should any adverse events occur whilst undertaking the research, NHS protocol will be followed to ensure patient safety. Due to the nature of the intervention any adverse events would be most likely to involve psychological wellbeing.

OVERSIGHT ARRANGEMENTS

INSPECTION OF RECORDS

Investigators and institutions involved in the study will permit trial related monitoring and audits on behalf of the sponsor, REC review, and regulatory inspection(s). In the event of audit or monitoring, the Investigator agrees to allow the representatives of the sponsor direct access to all study records and source documentation. In the event of regulatory inspection, the Investigator agrees to allow inspectors direct access to all study records and source documentation.

RISK ASSESSMENT

A study specific risk assessment will be performed by representatives of the co-sponsors, ACCORD monitors and the QA group, in accordance with ACCORD governance and sponsorship SOPs. Input will be sought from the Chief Investigator or designee. The outcomes of the risk assessment will form the basis of the monitoring plans and audit plans. The risk assessment outcomes will also indicate which risk adaptions (delete if no adaptations were possible) could be incorporated into to trial design.

STUDY MONITORING AND AUDIT

The ACCORD Sponsor Representative will assess the study to determine if an independent risk assessment is required. If required, the independent risk assessment will be carried out by the ACCORD Quality Assurance Group to determine if an audit should be performed before/during/after the study and, if so, at what frequency.

Risk assessment, if required, will determine if audit by the ACCORD QA group is required. Should audit be required, details will be captured in an audit plan. Audit of Investigator sites, study management activities and study collaborative units, facilities and 3rd parties may be performed.

GOOD CLINICAL PRACTICE

ETHICAL CONDUCT

The study will be conducted in accordance with the principles of the International Conference on Harmonisation Tripartite Guideline for Good Clinical Practice (ICH GCP).

Before the study can commence, all required approvals will be obtained and any conditions of approvals will be met.

INVESTIGATOR RESPONSIBILITIES

The Investigator is responsible for the overall conduct of the study at the site and compliance with the protocol and any protocol amendments. In accordance with the principles of ICH GCP, the following areas listed in this section are also the responsibility of the Investigator. Responsibilities may be delegated to an appropriate member of study site staff.

Informed Consent

The Investigator is responsible for ensuring informed consent is obtained before any protocol specific procedures are carried out. The decision of a participant to participate in clinical research is voluntary and should be based on a clear understanding of what is involved.

Participants must receive adequate oral and written information – appropriate Participant Information and Informed Consent Forms will be provided. The oral explanation to the participant will be performed by the Investigator or qualified delegated person, and must cover all the elements specified in the Participant Information Sheet and Consent Form.

The participant must be given every opportunity to clarify any points they do not understand and, if necessary, ask for more information. The participant must be given sufficient time to consider the information provided. It should be emphasised that the participant may withdraw their consent to participate at any time without loss of benefits to which they otherwise would be entitled.

The participant will be informed and agree to their medical records being inspected by regulatory authorities and representatives of the sponsor(s).

The Investigator or delegated member of the trial team and the participant will sign and date the Informed Consent Form(s) to confirm that consent has been obtained. The participant will receive a copy of this document and a copy filed in the Investigator Site File (ISF) and participant's medical notes (if applicable).

Study Site Staff

The Investigator must be familiar with the protocol and the study requirements. It is the Investigator's responsibility to ensure that all staff assisting with the study are adequately informed about the protocol and their trial related duties.

Data Recording

The chief investigator is responsible for the quality of the data recorded.

Investigator Documentation

The Principal Investigator will ensure that the required documentation is available in local Investigator Site files ISFs.

GCP Training

The Chief Investigator and academic supervisor have undertaken an introduction to GCP training, as recommended for non-CTIMP studies.

Confidentiality

All source information will collated into one database. Within this only participant numbers will be referred to. There will be a separate secure database in which participant numbers relate to identifiable information. All databases will be password protected which only the researcher and clinical supervisor will have access to. All hard copies of information i.e. battery questionnaires and diaries will be stored in a locked cabinet within the NHS Lothian's Clinical Health Psychology department at the Astley Ainslie hospital. Clinical information will be not be released without the written permission of the participant. The Investigator and study site staff involved with this study may not disclose or use for any purpose other than performance of the study, any data, record, or other unpublished, confidential information disclosed to those individuals for the purpose of the study. Prior written agreement from the sponsor or its designee will be obtained for the disclosure of any said confidential information to other parties.

Data Protection

All Investigator and study site staff involved with this study must comply with the requirements of the Data Protection Act 2018 with regard to the collection, storage, processing and disclosure of personal information and will uphold the Act's core principles. Access to collated participant data will be restricted to individuals from the research team treating the participants, representatives of the sponsor and representatives of regulatory authorities.

Computers used to collate the data will have limited access measures via user names and passwords.

Published results will not contain any personal data that could allow identification of individual participants.

STUDY CONDUCT RESPONSIBILITIES

PROTOCOL AMENDMENTS

Any changes in research activity, except those necessary to remove an apparent, immediate hazard to the participant in the case of an urgent safety measure, will be reviewed and approved by the Chief Investigator.

Amendments will be submitted to a sponsor representative for review and authorisation before being submitted in writing to the appropriate REC, and local R&D for approval prior to participants being enrolled into an amended protocol.

MANAGEMENT OF PROTOCOL NON COMPLIANCE

Prospective protocol deviations, i.e. protocol waivers, will not be approved by the sponsors and therefore will not be implemented, except where necessary to eliminate an immediate hazard to study participants. If this necessitates a subsequent protocol amendment, this should be submitted to the REC, and local R&D for review and approval if appropriate.

Protocol deviations will be recorded in a protocol deviation log and logs will be submitted to the sponsors every 3 months. Each protocol violation will be reported to the sponsor within 3 days of becoming aware of the violation. All protocol deviation logs and violation forms should be emailed to QA@accord.scot

Deviations and violations are non-compliance events discovered after the event has occurred. Deviation logs will be maintained for each site in multi-centre studies. An alternative frequency of deviation log submission to the sponsors may be agreed in writing with the sponsors.

SERIOUS BREACH REQUIREMENTS

A serious breach is a breach which is likely to effect to a significant degree:

(a) the safety or physical or mental integrity of the participants of the trial; or

(b) the scientific value of the trial.

If a potential serious breach is identified by the Chief investigator or delegates, the sponsor (seriousbreach@accord.scot) must be notified within 24 hours. It is the responsibility of the co-sponsors to assess the impact of the breach on the scientific value of the trial, to determine whether the incident constitutes a serious breach and report to research ethics committees as necessary.

STUDY RECORD RETENTION

All study documentation will be kept for a minimum of 10 years from the protocol defined end of study point. When the minimum retention period has elapsed, study documentation will not be destroyed without permission from the sponsor.

END OF STUDY

The end of study is defined as either the participant's last session of the Rebalance group, or the last day of daily data collection at 3 month follow up if they choose to participate in additional daily data collection.

The Investigators or the sponsor have the right at any time to terminate the study for clinical or administrative reasons.

The end of the study will be reported to the REC, and R+D Office and sponsor within 90 days, or 15 days if the study is terminated prematurely. The Investigators will inform participants of the premature study closure and ensure that the appropriate follow up is arranged for all participants involved. End of study notification will be reported to the co-sponsors via email to resgov@accord.scot.

A summary report of the study will be provided to the REC within 1 year of the end of the study.

CONTINUATION OF TREATMENT FOLLOWING THE END OF STUDY

Continued intervention through the Clinical Health Psychology department will be determined following completion of the Rebalance group. All participants are invited to attend a review appointment with a group facilitator (Clinical Psychologist) to determine further intervention plan, if required.

INSURANCE AND INDEMNITY

The co-sponsors are responsible for ensuring proper provision has been made for insurance or indemnity to cover their liability and the liability of the Chief Investigator and staff.

The following arrangements are in place to fulfil the co-sponsors' responsibilities:

The Protocol has been designed by the Chief Investigator and researchers employed by the University and collaborators. The University has insurance in place (which includes no-fault compensation) for negligent harm caused by poor protocol design by the Chief Investigator and researchers employed by the University.

Sites participating in the study will be liable for clinical negligence and other negligent harm to individuals taking part in the study and covered by the duty of care owed to them by the sites concerned. The co-sponsors require individual sites participating in the study to arrange for their own insurance or indemnity in respect of these liabilities.

Sites which are part of the United Kingdom's National Health Service will have the benefit of NHS Indemnity.

Sites out with the United Kingdom will be responsible for arranging their own indemnity or insurance for their participation in the study, as well as for compliance with local law applicable to their participation in the study.

REPORTING, PUBLICATIONS AND NOTIFICATION OF RESULTS

AUTHORSHIP POLICY

Ownership of the data arising from this study resides with the study team.

REFERENCES

A-Tjak, J., Davis, M., Morina, N., Powers, M., Smits J, & Emmelkamp, P. (2015). A Meta-Analysis of the Efficacy of Acceptance and Commitment Therapy for Clinically Relevant Mental and Physical Health Problems. *Psychotherapy and Psychosomatics*, *84*, 30–36. https://doi.org/10.1159/000365764

Agostinis, A. (2007). The Development of a Microsoft Excel File for Psychologists in Clinical Training and Clinical Psychologists : The ‘ Leeds Reliable Change Index. *Change*.

Andrews, B., Qian, M., & Valentine, J. D. (2002). Predicting depressive symptoms with a new measure of shame: The Experience of Shame Scale. *British Journal of Clinical Psychology*, *41*(1), 29–42. https://doi.org/10.1348/014466502163778

Ashworth, F., Clarke, A., Jones, L., Jennings, C., & Longworth, C. (2014). An exploration of compassion focused therapy following acquired brain injury. *Psychology and Psychotherapy: Theory, Research and Practice*. https://doi.org/10.1111/papt.12037

Austin, J., Drossaert, C. H. C., Schroevers, M. J., Sanderman, R., Kirby, J. N., & Bohlmeijer, E. T. (2020).

Compassion-based interventions for people with long-term physical conditions: a mixed methods systematic review. *Psychology & Health*, 1–27. https://doi.org/10.1080/08870446.2019.1699090

Barnett, K., Mercer, S. W., Norbury, M., Watt, G., Wyke, S., & Guthrie, B. (2012). Epidemiology of multimorbidity and implications for health care, research, and medical education: A cross-sectional study. *The Lancet*, *380*(9836), 37–43. https://doi.org/10.1016/S0140-6736(12)60240-2

Baumeister, R. F., & Leary, M. R. (1995). The Need to Belong: Desire for Interpersonal Attachments as a Fundamental Human Motivation. *Psychological Bulletin*, *117*(3), 497–529. https://doi.org/10.1037/0033-2909.117.3.497

Baumeister, R. F., Stillwell, A. M., & Heatherton, T. F. (1994). Guilt: An interpersonal approach. *Psychological Bulletin*, *115*(2), 243–267. https://doi.org/10.1037/0033-2909.115.2.243

Bernard, H., Burlingame, G., Flores, P., Greene, L., Joyce, A., Kobos, J. C., … Feirman, D. (2008). Clinical Practice Guidelines for Group Psychotherapy. *International Journal of Group Psychotherapy*, *58*(4).

Biber, D. D., & Ellis, R. (2019, December 1). The effect of self-compassion on the self-regulation of health behaviors: A systematic review. *Journal of Health Psychology*. SAGE Publications Ltd. https://doi.org/10.1177/1359105317713361

Birchwood, M., Jackson, C., Brunet, K., Holden, J., & Barton, K. (2012). Personal beliefs about illness questionnaire-revised (PBIQ-R): Reliability and validation in a first episode sample. *British Journal of Clinical Psychology*, *51*(4), 448–458. https://doi.org/10.1111/j.2044-8260.2012.02040.x

Boquiren, V. M., Esplen, M. J., Wong, J., Toner, B., & Warner, E. (2013). Exploring the influence of gender-role socialization and objectified body consciousness on body image disturbance in breast cancer survivors. *Psycho-Oncology*, *22*(10), n/a-n/a. https://doi.org/10.1002/pon.3271

Brassington, L., Ferreira, N. B., Yates, S., Fearn, J., Lanza, P., Kemp, K., & Gillanders, D. (2016). Better living with illness: A transdiagnostic acceptance and commitment therapy group intervention for chronic physical illness. *Journal of Contextual Behavioral Science*. https://doi.org/10.1016/j.jcbs.2016.09.001

Brion, J., Leary, M., & Drabkin, A. (2014). Self-compassion and reactions to serious illness: the case of HIV., 218–229. https://doi.org/10.1177/1359105312467391

Brion, J. M., Leary, M. R., & Drabkin, A. S. (2014). Self-compassion and reactions to serious illness: The case of HIV. *Journal of Health Psychology*, *19*(2), 218–229. https://doi.org/10.1177/1359105312467391

British Psychological Society, T. (2008). Clinical Health Psychologists in the NHS.

Brossart, D. F., Laird, V. C., & Armstrong, T. W. (2018). Interpreting Kendall's Tau and Tau-U for single-case experimental designs. *Cogent Psychology*, *5*(1), 1–26. https://doi.org/10.1080/23311908.2018.1518687

Campos, R. C., Besser, A., Ferreira, R., & Blatt, S. J. (2012). Self-criticism, neediness, and distress among women undergoing treatment for breast cancer: A preliminary test of the moderating role of adjustment to illness. *International Journal of Stress Management*, *19*(2), 151–174.

https://doi.org/10.1037/a0027996

Casati, J., Toner, B. B., De Rooy, E. C., Drossman, D. A., & Maunder, R. G. (2000). Concerns of patients with inflammatory bowel disease: A review of emerging themes. *Digestive Diseases and Sciences*. Springer. https://doi.org/10.1023/A:1005492806777

Castonguay, A. L., Wrosch, C., Pila, E., & Sabiston, C. M. (2017). Body-related shame and guilt predict physical activity in breast cancer survivors over time. *Oncology Nursing Forum*, *44*(4), 465–475. https://doi.org/10.1188/17.ONF.465-475

Chida, Y., Hamer, M., & Steptoe, A. (2008). A Bidirectional Relationship Between Psychosocial Factors and Atopic Disorders: A Systematic Review and Meta-Analysis. *Psychosomatic Medicine*, *70*(1), 102–116. https://doi.org/10.1097/PSY.0b013e31815c1b71

Clark, A. (2012). Working with guilt and shame . *Advances in Psychiatric Treatment*, *18*, 137–143. https://doi.org/10.1192/apt.bp.110.008326

Clegg, S., Sirois, F., & Reuber, M. (2019). Self-compassion and adjustment in epilepsy and psychogenic nonepileptic seizures. *Epilepsy and Behavior*, *100*(Pt A), 106490. https://doi.org/10.1016/j.yebeh.2019.106490

Conradt, M., Dierk, J.-M., Schlumberger, P., Rauh, E., Hebebrand, J., & Rief, W. (2007a). Development of the Weight- and Body-Related Shame and Guilt Scale (WEB–SG) in a Nonclinical Sample of Obese Individuals. *Journal of Personality Assessment*, *88*(3), 317–327. https://doi.org/10.1080/00223890701331856

Conradt, M., Dierk, J. M., Schlumberger, P., Rauh, E., Hebebrand, J., & Rief, W. (2007b). Development of the weight- and body-related shame and guilt scale (WEB-SG) in a nonclinical sample of obese individuals. *Journal of Personality Assessment*, *88*(3), 317–327. https://doi.org/10.1080/00223890701331856

Cuppage, J., Baird, K., Gibson, J., Booth, R., & Hevey, D. (2018). Compassion focused therapy: Exploring the effectiveness with a transdiagnostic group and potential processes of change. *British Journal of Clinical Psychology*, *57*(2), 240–254. https://doi.org/10.1111/bjc.12162

Davids, E. ., & Roman, N. . (2014). A systematic review of the relationship between parenting styles and children's physical activity. *African Journal for Physical Health Education*, *20*(2), 228–246.

de Ridder, D., Geenen, R., Kuijer, R., & van Middendorp, H. (2008). Psychological adjustment to chronic disease. *The Lancet*, *372*(9634), 246–255. https://doi.org/10.1016/S0140-6736(08)61078-8

Dekker, J., & de Groot, V. (2018). Psychological adjustment to chronic disease and rehabilitation – an exploration. *Disability and Rehabilitation*, *40*(1), 116–120. https://doi.org/10.1080/09638288.2016.1247469

Department of Health. (2012). *Long Term Conditions Compendium of Information Third Edition*.

Dewsaran-van der Ven, C., van Broeckhuysen-Kloth, S., Thorsell, S., Scholten, R., De Gucht, V., & Geenen, R. (2018). Self-compassion in somatoform disorder. *Psychiatry Research*, *262*, 34–39. https://doi.org/10.1016/J.PSYCHRES.2017.12.013

Dolezal, L., & Lyons, B. (2017). Health-related shame: An affective determinant of health? *Medical Humanities*, *43*(4), 257–263. https://doi.org/10.1136/medhum-2017-011186

Dunkley, D. M., Schwartzman, D., Looper, K. J., Sigal, J. J., Pierre, A., & Kotowycz, M. A. (2012). Perfectionism dimensions and dependency in relation to personality vulnerability and psychosocial adjustment in patients with coronary artery disease. *Journal of Clinical Psychology in Medical Settings*, *19*(2), 211–223. https://doi.org/10.1007/s10880-011-9271-2

Evers, A. W., Kraaimaat, F. W., van Lankveld, W., Jongen, P. J., Jacobs, J. W., & Bijlsma, J. W. (2001). Beyond unfavorable thinking: the illness cognition questionnaire for chronic diseases. *Journal of Consulting and Clinical Psychology*, *69*(6), 1026–1036.

Fellows, J. L., Flower, L., Blakey, J., Kurukulaaratchy, R., Howard, R., & Mansur, A. (2015). Case series: The application of "third wave" cognitive behavioural therapies in difficult to treat asthma. *Journal of Asthma*. https://doi.org/10.3109/02770903.2014.1003155

Firth-Cozens, J., & Cornwell, J. (2009). *The point of care: Enabling compassionate care in acute hospital settings*. London.

Friis, A., Johnson, M., … R. C.-D., & 2016, undefined. (n.d.). Kindness matters: a randomized controlled trial of a mindful self-compassion intervention improves depression, distress, and HbA1c among patients with diabetes. *Am Diabetes Assoc*.

Gilbert, P., Durrant, R., & McEwan, K. (2006). Investigating relationships between perfectionism, forms and functions of self-criticism, and sensitivity to put-down. *Personality and Individual Differences*, *41*(7), 1299–1308. https://doi.org/10.1016/j.paid.2006.05.004

Gilbert, P, & Andrews, B. (1998). *Shame: Interpersonal Behavior, Psychopathology, and Culture*. Oxford University Press.

Gilbert, P, & Miles, J. (2014). *Body Shame: Conceptualisation, Research and Treatment*. London: Routledge.

Gilbert, Paul. (1997). The evolution of social attractiveness and its role in shame, humiliation, guilt and therapy. *British Journal of Medical Psychology*, *70*(2), 113–147. https://doi.org/10.1111/j.2044-8341.1997.tb01893.x

Gilbert, Paul. (2000). The relationship of shame, social anxiety and depression: the role of the evaluation of social rank. *Clinical Psychology & Psychotherapy*, *7*(3), 174–189. https://doi.org/10.1002/1099-0879(200007)7:3<174::AID-CPP236>3.0.CO;2-U

Gilbert, Paul. (2014). The origins and nature of compassion focused therapy. *British Journal of Clinical Psychology*, *53*(1), 6–41. https://doi.org/10.1111/bjc.12043

Gilbert, Paul, Catarino, F., Duarte, C., Matos, M., Kolts, R., Stubbs, J., … Basran, J. (2017). The development of compassionate engagement and action scales for self and others. *Journal of Compassionate Health Care*, *4*(1), 4. https://doi.org/10.1186/s40639-017-0033-3

Gilbert, Paul, & Procter, S. (2006). Compassionate mind training for people with high shame and self-criticism: overview and pilot study of a group therapy approach. *Clinical Psychology & Psychotherapy*, *13*(6), 353–379. https://doi.org/10.1002/cpp.507

Harandi, T. F., Taghinasab, M. M., & Nayeri, T. D. (2017). The correlation of social support with mental health: A meta-analysis. *Electronic Physician*, *9*(9), 5212–5222. https://doi.org/10.19082/5212

Harder, D. W., Cutler, L., & Rockart, L. (1992). Assessment of Shame and Guilt and Their Relationships to Psychopathology. *Journal of Personality Assessment*, *59*(3), 584–604.

https://doi.org/10.1207/s15327752jpa5903_12

Hayes, S. C., Luoma, J. B., Bond, F. W., Masuda, A., & Lillis, J. (2006). Acceptance and Commitment Therapy: Model, processes and outcomes . *Behaviour Research and Therapy*, 44 (1), 1–25.

Hill, J., Holcombe, C., Clark, L., Boothby, M. R. K., Hincks, A., Fisher, J., … Salmon, P. (2011). Predictors of onset of depression and anxiety in the year after diagnosis of breast cancer. *Psychological Medicine*, *41*(7), 1429–1436. https://doi.org/10.1017/S0033291710001868

Hutchinson, P., & Dhairyawan, R. (2017). Shame, stigma, HIV: Philosophical reflections. *Medical Humanities*, *43*(4), 225–230. https://doi.org/10.1136/medhum-2016-011179

Hyphantis, T., Goulia, P., & Carvalho, A. F. (2013). Personality traits, defense mechanisms and hostility features associated with somatic symptom severity in both health and disease. *Journal of Psychosomatic Research*, *75*(4), 362–369. https://doi.org/10.1016/j.jpsychores.2013.08.014

Inwood, E., & Ferrari, M. (2018). Mechanisms of Change in the Relationship between Self-Compassion, Emotion Regulation, and Mental Health: A Systematic Review. *Applied Psychology: Health and Well-Being*. https://doi.org/10.1111/aphw.12127

Jacobson, N. S., & Truax, P. (1991). Clinical Significance: A Statistical Approach to Defining Meaningful Change in Psychotherapy Research. *Journal of Consulting and Clinical Psychology*, *59*(1), 12–19. https://doi.org/10.1037/0022-006X.59.1.12

James, K., Verplanken, B., & Rimes, K. A. (2015). Self-criticism as a mediator in the relationship between unhealthy perfectionism and distress. *Personality and Individual Differences*, *79*, 123–128. https://doi.org/10.1016/j.paid.2015.01.030

Judge, L., Cleghorn, A., McEwan, K., & Gilbert, P. (2012). An Exploration of Group-Based Compassion Focused Therapy for a Heterogeneous Range of Clients Presenting to a Community Mental Health Team. *International Journal of Cognitive Therapy*, *5*, 420–429.

Kaufman, G. (1996). *The psychology of shame: Theory and treatment of shame-based syndromes*. Springer. https://doi.org/10.1016/s0191-8869(97)85593-6

Kim, S., Thibodeau, R., & Jorgensen, R. S. (2011). Shame, Guilt, and Depressive Symptoms: A Meta-Analytic Review. *Psychological Bulletin*, *137*(1), 68–96. https://doi.org/10.1037/a0021466

Kirby, J. N., Tellegen, C. L., & Steindl, S. R. (2017). A Meta-Analysis of Compassion-Based Interventions: Current State of Knowledge and Future Directions. *Behavior Therapy*, *48*, 778–792. https://doi.org/10.1016/j.beth.2017.06.003

Kolts, R. L. (2016). *CFT made simple : a clinician's guide to practicing compassion-focused therapy*.

Kupfer, J., Brosig, B., Niemeier, V., & Gieler, U. (2005). Zur Validität des Hautzufriedenheitsbogens (Hautzuf)–Validity of the Touch-Shame-Disgust-Questionnaire (TSD-Q). *Psychother Psychosom Med*.

Lahousen, T., Kupfer, J., Gieler, U., Hofer, A., Linder, M. D., & Schut, C. (2016). Differences between psoriasis patients and skin-healthy controls concerning appraisal of touching, shame and disgust. *Acta Dermato-Venereologica*, *96*, 78–82. https://doi.org/10.2340/00015555-2373

Lastrucci, V., Lorini, C., Caini, S., Florence Health Literacy Research Group, & Bonaccorsi, G. (2019). Health literacy as a mediator of the relationship between socioeconomic status and health: A cross-sectional study in a population-based sample in Florence. *PloS One*, *14*(12), e0227007.

https://doi.org/10.1371/journal.pone.0227007

Lazare, A. (1987). Shame and Humiliation in the Medical Encounter, *147*.

Leaviss, J., & Uttley, L. (2015). Psychotherapeutic benefits of compassion-focused therapy: an early systematic review. *Psychological Medicine*, *45*(05), 927–945. https://doi.org/10.1017/S0033291714002141

Lindsey, S. (2017). *Examining the Psychometric Properties of the Compassionate Engagement and Action Scales in the General Population*.

Lorig, K. R., Ritter, P., Stewart, A. L., Sobel, D. S., Brown, B. W., Bandura, A., … Holman, H. R. (2001). Chronic disease self-management program: 2-year health status and health care utilization outcomes. *Medical Care*, *39*(11), 1217–1223.

MacBeth, A., & Gumley, A. (2012a). Exploring compassion: A meta-analysis of the association between self-compassion and psychopathology. *Clinical Psychology Review*. https://doi.org/10.1016/j.cpr.2012.06.003

MacBeth, A., & Gumley, A. (2012b). Exploring compassion: A meta-analysis of the association between self-compassion and psychopathology. *Clinical Psychology Review*, *32*(6), 545–552. https://doi.org/10.1016/J.CPR.2012.06.003

Maddison, A., Halliday, G., & Gillanders, D. (2020). Illness-related shame and associated outcomes: A systematic review. *Journal of Behavioral Medicine*, *in prep*.

McFall, L., & Johnson, V. (2009). Shame: Concept Analysis. *Journal of Theory Construction & Testing*, *13*(2), 57–63.

Mckinley, N. M., & Hyde, J. S. (1996). *The Objectified Body Consciousness Scale Development and Validation*. *Psychology of Women Quarterly* (Vol. 20).

Mehr, K. E., & Adams, A. C. (2016). Self-Compassion as a Mediator of Maladaptive Perfectionism and Depressive Symptoms in College Students. *Journal of College Student Psychotherapy*, *30*(2), 132–145. https://doi.org/10.1080/87568225.2016.1140991

Minja, L., Cichowitz, C., Knettel, B. A., Mahande, M. J., Kisigo, G., Knippler, E. T., … Watt, M. H. (2019). Attitudes Toward Long-Term Use of Antiretroviral Therapy Among HIV-Infected Pregnant Women in Moshi, Tanzania: A Longitudinal Study. *AIDS and Behavior*, *23*(9), 2610–2617. https://doi.org/10.1007/s10461-019-02622-5

Moreira, H., & Canavarro, M. C. (2010). A longitudinal study about the body image and psychosocial adjustment of breast cancer patients during the course of the disease. *European Journal of Oncology Nursing*, *14*(4), 263–270. https://doi.org/10.1016/j.ejon.2010.04.001

Moreira, H., Silva, S., Marques, A., & Canavarro, M. C. (2010). The Portuguese version of the Body Image Scale (BIS) - psychometric properties in a sample of breast cancer patients. *European Journal of Oncology Nursing*, *14*(2), 111–118. https://doi.org/10.1016/j.ejon.2009.09.007

Morley, S., & Dowzer, C. N. (2014). *The Leeds Reliable Change Indicator* .

Moss-Morris, R. (2013). Adjusting to chronic illness: Time for a unified theory. *British Journal of Health Psychology*, *18*(4), 681–686. https://doi.org/10.1111/bjhp.12072

Mundt, J. C., Marks, I. M., Shear, M. K., & Greist, J. H. (2002). The Work and Social Adjustment Scale:

a simple measure of impairment in functioning. *The British Journal of Psychiatry : The Journal of Mental Science*, *180*, 461–464.

National Institute for Health and Care Excellence. (2017). Overview | Multimorbidity | Quality standards | NICE. Retrieved April 6, 2020, from https://www.nice.org.uk/guidance/qs153

Naylor, C., Das, P., Ross, S., Honeyman, M., Thompson, J., & Gilburt, H. (2016). Bringing together physical and mental health A new frontier for integrated care.

Naylor, C., Parsonage, M., Mcdaid, D., Knapp, M., Fossey, M., & Galea, A. (2012). Long-term conditions and mental health The cost of co-morbidities.

Neff, K. D. (2011). Self-Compassion, Self-Esteem, and Well-Being. *Social and Personality Psychology Compass*, *5*, 1–12. https://doi.org/10.1111/j.1751-9004.2010.00330.x

Neufeld, S. A. S., Sikkema, K. J., Lee, R. S., Kochman, A., & Hansen, N. B. (2012). The Development and Psychometric Properties of the HIV and Abuse Related Shame Inventory (HARSI). *AIDS and Behavior*, *16*, 1063–1074. https://doi.org/10.1007/s10461-011-0086-9

Ohrnberger, J., Fichera, E., & Sutton, M. (2017). The relationship between physical and mental health: A mediation analysis. *Social Science and Medicine*, *195*, 42–49. https://doi.org/10.1016/j.socscimed.2017.11.008

Parker, R. I., Vannest, K. J., & Davis, J. L. (2011). Effect size in single-case research: a review of nine nonoverlap techniques. *Behavior Modification*, *35*(4), 303–322. https://doi.org/10.1177/0145445511399147

Parker, R. I., Vannest, K. J., Davis, J. L., & Sauber, S. B. (2011). Combining Nonoverlap and Trend for Single-Case Research: Tau-U. *Behavior Therapy*, *42*(2), 284–299. https://doi.org/10.1016/j.beth.2010.08.006

Persons, E., Kershaw, T., Sikkema, K. J., & Hansen, N. B. (2010). The Impact of Shame on Health-Related Quality of Life Among HIV-Positive Adults with a History of Childhood Sexual Abuse. *AIDS Patient Care and STDs*, *24*(9), 571–580. https://doi.org/10.1089/apc.2009.0209

Pila, E., Sabiston, C. M., Castonguay, A. L., Arbour-Nicitopoulos, K., & Taylor, V. H. (2018). Mental health consequences of weight cycling in the first-year post-treatment for breast cancer. *Psychology & Health*, *33*(8), 995–1013. https://doi.org/10.1080/08870446.2018.1453510

Renn, B. N., Feliciano, L., & Segal, D. L. (2011, December 1). The bidirectional relationship of depression and diabetes: A systematic review. *Clinical Psychology Review*. Pergamon. https://doi.org/10.1016/j.cpr.2011.08.001

Ritter, P. L., & Lorig, K. (2014). The English and Spanish Self-Efficacy to Manage Chronic Disease Scale measures were validated using multiple studies. *Journal of Clinical Epidemiology*, *67*(11), 1265–1273. https://doi.org/10.1016/j.jclinepi.2014.06.009

Roman, N. V, & Frantz, J. M. (2013). The prevalence of intimate partner violence in the family: a systematic review of the implications for adolescents in Africa. https://doi.org/10.1093/fampra/cms084

Royal College of Psychiatrists. (2013). *Liaison psychiatry for every acute hospital* . London.

Rudich, Z., Lerman, S. F., Gurevich, B., Weksler, N., & Shahar, G. (2008). Patients' Self-Criticism Is a Stronger Predictor of Physician's Evaluation of Prognosis Than Pain Diagnosis or Severity in

Chronic Pain Patients. *Journal of Pain*, *9*(3), 210–216. https://doi.org/10.1016/j.jpain.2007.10.013

Scottish Government. (2015a). Long Term Conditions. Retrieved June 5, 2018, from http://www.gov.scot/Topics/Health/Services/Long-Term-Conditions

Scottish Government. (2015b). *The Matrix (2015) A Guide to Delivering Evidence-Based Psychological Therapies in Scotland*.

Sharpe, L., & Curran, L. (2006). Understanding the process of adjustment to illness. *Social Science & Medicine*, *62*, 1153–1166. https://doi.org/10.1016/j.socscimed.2005.07.010

Sikkema, K. J., Hansen, N. B., Meade, C. S., Kochman, A., & Fox, A. M. (2009). Psychosocial predictors of sexual HIV transmission risk behavior among HIV-positive adults with a sexual abuse history in childhood. *Archives of Sexual Behavior*, *38*(1), 121–134. https://doi.org/10.1007/s10508-007-9238-4

Sirois, F. M., Molnar, D. S., & Hirsch, J. K. (2015). Self-Compassion, Stress, and Coping in the Context of Chronic Illness. *Self and Identity*, *14*(3), 334–347. https://doi.org/10.1080/15298868.2014.996249

Sirois, F. M., Rowse, G., & Review, D. C. (2016). *The Role of Self-Compassion in Chronic Illness Care*. *www.jcomjournal.com* (Vol. 23).

Taal, L. A., & Faberb, A. W. (1998). Posttraumatic stress and maladjustment among adult burn survivors l-2 years postburn. *Burns* (Vol. 24).

Taal, L., & Faber, A. W. (1998). Posttraumatic stress and maladjustment among adult burn survivors 1 to 2 years postburn Part II: the interview data. *Burns* (Vol. 24).

Takahashi, H., Yahata, N., Koeda, M., Matsuda, T., Asai, K., Okubo, Y., & Hospital, A. (2004). Brain activation associated with evaluative processes of guilt and embarrassment: an fMRI study. N*euroimage,* 23(3), 967-974 https://doi.org/10.1016/j.neuroimage.2004.07.054

Tangney, J. P., Miller, R. S., Flicker, L., & Barlow, D. H. (1996). Are shame, guilt, and embarrassment distinct emotions? *Journal of Personality and Social Psychology*, *70*(6), 1256–1269. https://doi.org/10.1037//0022-3514.70.6.1256

Tennant, R., Hiller, L., Fishwick, R., Platt, S., Joseph, S., Weich, S., … Stewart-Brown, S. (2007). Health and Quality of Life Outcomes The Warwick-Edinburgh Mental Well-being Scale (WEMWBS): development and UK validation. https://doi.org/10.1186/1477-7525-5-63

Thomas, K. H., Martin, R. M., Potokar, J., Pirmohamed, M., & Gunnell, D. (2014). Reporting of drug induced depression and fatal and non-fatal suicidal behaviour in the UK from 1998 to 2011. *BMC Pharmacology and Toxicology*, *15*(1), 54. https://doi.org/10.1186/2050-6511-15-54

Tirch, D., Schoendorff, B., & Silberstein, L. . (2014). *The ACT Practitioner's Guide to the Science of Compassion: Tools for fostering psychological flexibility*. New Harbringer Publications, Inc.

Tracy, J., Robins, R., & Tangney, J. (2007). *The Self-conscious Emotions: Theory and Research* . Guildford Press.

Trindade, I. A., Duarte, J., Ferreira, C., Coutinho, M., & Pinto-Gouveia, J. (2018). The impact of illness-related shame on psychological health and social relationships: Testing a mediational model in students with chronic illness. *Clinical Psychology & Psychotherapy*, *25*(3), 408–414.

https://doi.org/10.1002/cpp.2175

Trindade, I. A., Ferreira, C., & Pinto-Gouveia, J. (2017a). Chronic Illness-Related Shame: Development of a New Scale and Novel Approach for IBD Patients' Depressive Symptomatology. *Clinical Psychology and Psychotherapy*, *24*(1), 255–263. https://doi.org/10.1002/cpp.2035

Trindade, I. A., Ferreira, C., & Pinto-Gouveia, J. (2017b). Chronic Illness-Related Shame: Development of a New Scale and Novel Approach for IBD Patients' Depressive Symptomatology. *Clinical Psychology & Psychotherapy*, *24*(1), 255–263. https://doi.org/10.1002/cpp.2035

Trindade, I. A., Irons, C., Ferreira, C., Portela, F., & Pinto-Gouveia, J. (2019). The influence of self-criticism on depression symptoms among ambulatory patients with inflammatory bowel disease. *Clinical Psychology & Psychotherapy*, *26*(6), 743–750. https://doi.org/10.1002/cpp.2398

Trindade, I. A., Marta-Simões, J., Ferreira, C., & Pinto-Gouveia, J. (2018). Developments on committed action: Validity of the CAQ-8 and analysis of committed action's role in depressive symptomatology in breast cancer patients and healthy individuals. *Clinical Psychology and Psychotherapy*, *25*(1), e42–e50. https://doi.org/10.1002/cpp.2125

Trindade, I. A., Marta-Simões, J., Ferreira, C., & Pinto-Gouveia, J. (2018). Chronic illness-related cognitive fusion explains the impact of body dissatisfaction and shame on depression symptoms in breast cancer patients. *Clinical Psychology & Psychotherapy*, *25*(6), 886–893. https://doi.org/10.1002/cpp.2323

Trindade, I., Ferreira, C., & Pinto-Gouveia, J. (2017). Shame and emotion regulation in inflammatory bowel disease: Effects on psychosocial functioning. *Journal of Health Psychology* (0), 1–11. https://doi.org/10.1177/1359105317718925

Vincent, W., Fang, X., Calabrese, S. K., Heckman, T. G., Sikkema, K. J., & Hansen, N. B. (2017). HIV-related shame and health-related quality of life among older, HIV-positive adults. *Journal of Behavioral Medicine*, *40*(3), 434–444. https://doi.org/10.1007/s10865-016-9812-0

Werner, A., Isaksen, L. W., & Malterud, K. (2004). "I am not the kind of woman who complains of everything": Illness stories on self and shame in women with chronic pain. *Social Science and Medicine*, *59*(5), 1035–1045. https://doi.org/10.1016/j.socscimed.2003.12.001

Wiechelt, S. A. (2017). Substance Use & Misuse The Specter of Shame in Substance Misuse. https://doi.org/10.1080/10826080601142196

World Health Organization Regional Office for Europe (2017). *Addressing comorbidity between mental disorders and major noncommunicable diseases*.

Wong, W. C. W., Cheung, C. S. K., & Hart, G. J. (2008). Development of a quality assessment tool for systematic reviews of observational studies (QATSO) of HIV prevalence in men having sex with men and associated risk behaviours. *Emerging Themes in Epidemiology*. BioMed Central. https://doi.org/10.1186/1742-7622-5-23

Wren, A. A., Somers, T. J., Wright, M. A., Goetz, M. C., Leary, M. R., Fras, A. M., … Keefe, F. J. (2012). Self-Compassion in Patients With Persistent Musculoskeletal Pain: Relationship of Self-Compassion to Adjustment to Persistent Pain. *Journal of Pain and Symptom Management*, *43*, 759–770. https://doi.org/10.1016/j.jpainsymman.2011.04.014

Yakeley, J. (2018). Shame, culture and mental health. *Nordic Journal of Psychiatry*, *72*(sup1), S20–

S22. https://doi.org/10.1080/08039488.2018.1525641

Yalom, I. D., & Leszcz, M. (2005). *The theory and practice of group psychotherapy*. Basic Books.

Zessin, U., Dickhäuser, O., & Garbade, S. (2015). The Relationship Between Self-Compassion and Well-Being: A Meta-Analysis. *Applied Psychology: Health and Well-Being*, *7*(3), 340–364. https://doi.org/10.1111/aphw.12051

Academic and Clinical Central Office for Research and Development

Appendix Four – Participant Information Sheet and Consent Form

Participant Information Sheet and Consent Form

Rebalance: Group Compassion Focussed Therapy for people with transdiagnostic chronic health conditions – a case series.

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Contact us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

This study aims to help us understand how people find the Rebalance group helpful. We know that living with a long term health condition has physical, psychological and social consequences, all of which can be difficult to adjust to. The Rebalance group is an intervention in NHS Lothian for people living with long term physical health conditions. It uses Compassion Focussed Therapy (CFT) with the goal of helping people understand and learn new ways of responding to distress related to their conditions. The purpose of this study is to look at how people feel about themselves and their health condition while they are part of the group and if this changes as the group goes on.

Why have I been asked to take part?

You have been asked to take part as you have agreed to attend the Rebalance group in the Clinical Health Psychology department.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. Deciding not to take part or withdrawing from the study will not affect the healthcare that you receive, or your legal rights. If you decide to withdraw, or lose capacity to continue with the research, the anonymised data collected up to that point will be used in the analysis.

What will happen if I take part?

You will be asked to meet with the researcher around two weeks before the group starts, during this meeting we will ask for your consent to take part in the study, arrange when to begin and provide you with a paper diary for data collection.

You will be asked to answer three questions every day for a period of time before the group starts (maximum ten days) and while it runs, these take less than two minutes to complete. We will provide you with a diary that has the questions in for each day and will collect your answers each week before the group starts. During your meeting with the researcher we will talk to you about the best way to help you remember to answer the questions each day e.g. setting an alarm on your phone or putting it somewhere obvious in the house.

We will also ask you to complete a set of five paper questionnaires every week, these take around twenty minutes to complete. We will organise time for you to fill out the questionnaires before the group starts each week. At three months after the group it is usual to be followed up by the service which will involve completing the questionnaires again. At this point we may also ask you to complete the daily questions again for ten days, however, you do not have to do this if you do not wish to.

Overall the research will ask for a maximum of 7 hours of your time. This is:

- 30 minute appointment to sign consent form and plan how to use the daily diary.
- 2 minutes each day in your diary during baseline, group and follow up.
- 20 minutes before each group session and once at follow up.

The group will be the same for you as everyone else who has chosen not to be part of this research. The only difference will be the three questions to complete at home every day and completing questionnaires before the group each week. People not taking part in this study will also be asked to complete these questionnaires at the beginning and end of the nine weeks over which the group runs as part of our routine data collection.

What are the possible benefits of taking part?
There are no direct benefits to you taking part in this study whilst attending the Rebalance group, but the results of the study might help to inform future healthcare of other patients.

What are the possible disadvantages and risks of taking part?
It is not thought that there are any disadvantages; however, it is possible that you might find the additional time in the department (around 20 minutes each week) and answering questions each day (around two minutes each day) to be too much. If you do, you are free to withdraw. There is a possibility you may find some questions upsetting, if you do you can contact the staff leading the group or researcher on the number above and are free to withdraw from the study.

What happens when the study is finished?
At the end of the research we will destroy all the paper questionnaires and diaries and any links to your personal details. The data we keep will be: the responses to daily questions; questionnaire scores; information about your illness; number of times you have attended psychology before the group; age and; gender. Nothing we keep will be able to identify you. We will keep the anonymised data for up to ten years. The data is kept by the University of Edinburgh and NHS Lothian on their secure systems.

Will my taking part in the study be kept confidential?
All the information we collect during the course of the research will be kept confidential and there are strict laws which safeguard your privacy at every stage.
Study researchers will need access to your medical records to carry out this research.

With your consent we will inform your GP that you are taking part but they will not be told of any of the answers you provide.

To ensure that the study is being run correctly, we will ask your consent for responsible representatives from the Sponsor and NHS Institution to access your medical records and data collected during the study, where it is relevant to you taking part in this research. The Sponsor is responsible for overall management of the study and providing insurance and indemnity.

Academic and Clinical Central Office for Research and Development

What will happen to the results of the study?
The study will be written up as a journal article and submitted for publication, it may also be presented at conferences. You will not be identifiable in any published results. If you would like a summary of the results you can request this at any point and will be asked when giving consent to the study. We would post this to you when the study is finished and results have been analysed.

Who is organising the research and why?
This study has been organised/sponsored by NHS Lothian and the University of Edinburgh.

Who has reviewed the study?
The study proposal has been reviewed by Clinical Psychologists from NHS Lothian and The University of Edinburgh. All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee. A favourable ethical opinion has been obtained from South East Scotland Research Ethics Committee 2. NHS management approval has also been obtained.

If you have any further questions about the study please contact Anna Maddison on: 0131 537 9128 or email: anna.maddison@nhslothian.scot.nhs.uk

If you would like to discuss this study with someone independent of the study please contact:
Dr Ethel Quayle, University of Edinburgh: ethel.quayle@ed.ac.uk

If you wish to make a complaint about the study please contact NHS Lothian:
NHS Lothian Complaints Team
2nd Floor
Waverley Gate
2 - 4 Waterloo Place
Edinburgh
EH1 3EG
Tel: 0131 465 5708
complaints.team@nhslothian.scot.nhs.uk.

Thank you for taking the time to read this information sheet.

Academic and Clinical Central Office for Research and Development

CONSENT FORM

Compassion Focussed Therapy in a transdiagnostic health group

Participant ID: ☐

Anna Maddison, Trainee Clinical Psychologist
Anna.maddison@nhslothian.scot.nhs.uk, 0131 537 9128

Please initial box

1. I confirm that I have read and understand the information sheet V3.0., dated 24/05/2019 (as specified in this document header) for the above study and have had the opportunity to consider the information and ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the regulatory authorities and from the Sponsors (NHS Lothian and the University of Edinburgh) or from the/other NHS Board(s) where it is relevant to my taking part in this research. I give permission for those individuals to have access to my records. ☐
4. I agree that if I withdraw from the study, or lose capacity to continue with the research, any data previously collected can be used in the analysis. ☐
5. I agree to my General Practitioner being informed of my participation in this study ☐
6. I understand that the results of this study may be published in scholarly journals in a format in which I cannot be identified. ☐
7. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

1x original – into Site File; 1x copy – to Participant; 1x copy – into medical records

Appendix Five – Ethical approval

Lothian NHS Board

South East Scotland Research Ethics Committee 02

Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
Telephone 0131 536 9000

www.nhslothian.scot.nhs.uk

Date 17 January 2019
Your Ref
Our Ref

Enquiries to : Joyce Clearie
Extension: 35674
Direct Line: 0131 465 5674
Email: Joyce. Clearie@nhslothian.scot.nhs.uk

17 January 2019

Miss Anna Maddison
23 Grierson Crescent
Edinburgh
EH5 2AY

Dear Miss Maddison

Study title:	**Rebalance: Group Compassion Focussed Therapy for people with transdiagnostic chronic health conditions – a case series.**
REC reference:	**18/SS/0164**
Protocol number:	**CAHSS1810/04**
IRAS project ID:	**251582**

Thank you for your letter of 16th January 2019, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

NHS
Lothian

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).
Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

NHS
Lothian

Non-NHS sites

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
GP/consultant information sheets or letters [GP Notification Letter V2.0]		04 January 2019
IRAS Application Form [IRAS_Form_27112018]		27 November 2018
IRAS Application Form XML file [IRAS_Form_27112018]		27 November 2018
IRAS Checklist XML [Checklist_27112018]		27 November 2018
IRAS Checklist XML [Checklist_03122018]		03 December 2018
IRAS Checklist XML [Checklist_16012019]		16 January 2019
Other [Certificate of Employers' Liability Insurance(]		
Other [Certificate of Public Liability Insurance]		
Other [Clinical Trial Liability Insurance]		
Other [Professional Indemnity Insurance]		
Other [PO response to REC Cover Letter]		16 January 2019
Participant consent form [Consent Form V2.0]		04 January 2019
Participant information sheet (PIS) [Participant Information Sheet V2.0]		04 January 2019
Research protocol or project proposal [Protocol V2.0]		04 January 2019
Summary CV for Chief Investigator (CI) [Chief Investigator CV]		15 November 2018
Summary CV for student		
Summary CV for supervisor (student research)		
Validated questionnaire		
Validated questionnaire		
Validated questionnaire		
Validated questionnaire		
Validated questionnaire		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

18/SS/0164	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

Mr Lindsay Murray
Chair

Email:joyce.clearie@nhslothian.scot.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Charlotte Smith*
NHS Lothian Research and Development Office

Appendix Six – Journal of Behavioral Medicine submission guidelines

- Journal home
- Submission guidelines

Journal of Behavioral Medicine

Submission guidelines

Contents

- Instructions to Authors
  - Manuscript Submission
  - Types of Submissions Considered
  - Copyright
  - General
  - Manuscript Style
  - Page Charges
  - English Language Editing
  - Research Data Policy
  - Springer Open Choice
  - Ethical Responsibilities of Authors
  - Authorship principles
  - Compliance with Ethical Standards
  - Disclosure of potential conflicts of interest
  - Research involving human participants, their data or biological material
  - Informed consent

Instructions to Authors

Manuscript Submission

Manuscripts, in English, should be submitted to the Editor via the Journal's web-based online manuscript submission and peer-review system: http://jobm.edmgr.com

Inquiries regarding Journal policy and other such general topics should be sent to the Editor:

Alan Christensen, Ph.D.

e-mail to christensenal19@ecu.edu

http://jobm.edmgr.com

Back to top

Types of Submissions Considered

Regular Articles

The majority of journal pages are devoted to the publication of original empirical articles, such as reports of randomized controlled trials, observational studies, or other basic and clinical investigations within the domain of behavioral medicine. Quantitative or descriptive and integrative literature reviews will also be considered. Although the journal does not impose a strict page limit, it is strongly suggested that regular articles be no more than 30 double-spaced manuscript pages, including all figures, captions, tables, notes, and references.

Brief Report

Journal of Behavioral Medicine accepts brief reports of soundly designed research studies of specialized interest that can be effectively communicated in less space than standard-length articles. An author who submits a Brief Report must agree not to submit the full report to another journal. Brief Report submissions should not exceed a total of 15 double-spaced pages, including title page, abstract, references, tables, and figures.

Letters to the Editor

Journal of Behavioral Medicine may occasionally publish Letters to the Editor that offer opinion or interpretation of articles previously published in the journal. Letters should be limited to 500 words or less. Tables and figures should be used only if absolutely necessary. It is customary for letters to be sent to the author(s) of the original work and the authors' response may be published as a companion to the Letter to the Editor.

Back to top

Copyright

Submission is a representation that the manuscript has not been published previously and is not currently under consideration for publication elsewhere. A statement transferring copyright from the authors (or their employers, if they hold the copyright) to Springer will be required before the manuscript can be accepted for publication. Authors will receive an electronic notification to transfer copyright of the article to Springer Science+Business Media, LLC. Such a written transfer of copyright, which previously was assumed to be implicit in the act of submitting a manuscript, is necessary under the U.S. Copyright Law in order for the publisher to carry through the dissemination of research results and reviews as widely and effectively as possible.

Back to top

General

In general, Journal of Behavioral Medicine follows the recommendations of Publication Manual of the American Psychological Association, 6th Edition (2009), and it is suggested that contributors refer to this publication.

Back to top

Manuscript Style

- Although the journal does not impose a strict page limit, it is strongly suggested that manuscripts be no more than 25-30 double-spaced pages, including all figures, captions, tables, notes, and references.
- All pages should be typed double spaced and numbered (including pages containing the title, author name and affiliation footnotes,

abstract, acknowledgments, references, tables, and figure caption list).

- An abstract is to be provided, preferably no longer than 150 words. A list of 5-6 key words is to be provided directly below the abstract. Key words should express the precise content of the manuscript, as they are used for indexing purpose, both internal and external.
- Illustrations (photographs, drawings, diagrams, and charts) are to be numbered in one consecutive series of Arabic numerals. The captions for illustrations should be typed on a separate sheet of paper. Photographs should be large glossy prints, showing high contrast. Drawings should be prepared with india ink. Either the original drawings or good-quality photographic prints are acceptable. Identify figures on the back with author's name and number of the illustration. Electronic artwork submitted on disk should be in TIFF or EPS format (1200 dpi for line and 300 dpi for half-tones and gray-scale art). Color art should be in the CYMK color space. Artwork should be on a separate disk from the text, and hard copy must accompany the disk.
- Tables should be referred to by number in the text. Each table should be typed on a separate page. Both numbering and format should follow APA style.
- Electronic Supplementary MaterialsSpringer accepts electronic supplementary materials (animations, movies, audio, large original data, etc.) which will be published in the online version only. For detailed information about file formats, file size, etc., please check our ESM guidelines at http://www.springer.com/authors/manuscript+guidelines?SGWID=0-40162-12-339499-0
- List references alphabetically at the end of the paper and refer to them in the text by name and year in parentheses. In a slight departure from APA format, where there are three or more authors, only the first author's name is given in the text, followed by et al. References should include titles of papers and follow APA format in all other respects.
- The Journal of Behavioral Medicine requests that, whenever possible, statistical tests include a reporting of effects sizes. Authors are encouraged to report the relevant statistical information for both significant and non-significant effects, and to follow the statistical reporting recommendations presented in the Publication Manual of the American Psychological Association, 6th edition (2009).

Additional information can be found in “How to Report Statistics in Medicine” (Lang and Secic, 1997).

- For the reporting of intervention studies with randomized and nonrandomized designs, authors are requested to follow CONSORT (Consolidated Standards for Reporting of Trials; Moher, Jones, & Lepage, 2001) or TREND (Transparent Reporting of Evaluations with Nonrandomized Designs; Des Jarlais, Lyles, & Crepaz, 2004) guidelines to ensure that basic information about the conduct of studies is available. This information can be obtained online at “http://www.cdc.gov/trendstatement/
- For reporting of meta-analytic studies, authors are required to follow PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) (http://www.prisma-statement.org/) guidelines
- To enhance readability for a wide audience, the use of abbreviations and acronyms should be avoided throughout the manuscript. Exceptions include common statistical terminology (e.g., ANOVA) and widely recognized acronyms (e.g., US, NATO).
- Authors are responsible for all information in their work. If any tables, figures, or quotations from another source are adapted or used in entirety, permission must be granted from the copyright owner(s). Where applicable, authors are required to provide documentation of all permissions received.

http://www.springer.com/authors/manuscript+guidelines?SGWID=0-40162-12-339499-0

Back to top

Page Charges

The Journal makes no page charges. Reprints are available to authors, and order forms are sent with proofs.

Back to top

English Language Editing

For editors and reviewers to accurately assess the work presented in your manuscript you need to ensure the English language is of sufficient quality to be understood. If you need help with writing in English you should consider:

- Asking a colleague who is a native English speaker to review your manuscript for clarity.
- Visiting the English language tutorial which covers the common mistakes when writing in English.
- Using a professional language editing service where editors will improve the English to ensure that your meaning is clear and identify problems that require your review. Two such services are provided by our affiliates Nature Research Editing Service and American Journal Experts. Springer authors are entitled to a 10% discount on their first submission to either of these services, simply follow the links below.

English language tutorial

Nature Research Editing Service

American Journal Experts

Please note that the use of a language editing service is not a requirement for publication in this journal and does not imply or guarantee that the article will be selected for peer review or accepted.

If your manuscript is accepted it will be checked by our copyeditors for spelling and formal style before publication.